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HEALTH SELF-MANAGEMENT FOR ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

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HEALTH SELF-MANAGEMENT FOR ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

by

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Dedication

I dedicate this dissertation to my son Joshua. You are my hero! You overcome adversity every day in a world that challenges your heart and soul. This dissertation would not be if it were not for you instilling the passion and drive in me to make change happen. I hope this dissertation serves as a reminder to never stop advocating for yourself and others.

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Abstract

HEALTH SELF-MANAGEMENT FOR ADOLESCENTS WITH AUTISM SPECTRUM DISORDER

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Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition with differences in communication, social, and behavioral abilities diagnosed in 1 in 54 youth in the United States. Upwards of 95% of individuals with ASD have at least one co-occurring health condition, which may lead to early mortality in this population. Additionally, less than 14% of adolescents with ASD receive guided health transition services aimed to teach youth to self-manage their health throughout life. The gap in health transition services has left many parents with this responsibility. Therefore, given the dearth of research examining transition of health responsibility from parent to adolescent with ASD this study had three specific aims: to explore factors associated with adolescent health self-management (HSM) behavior, compare differences in parent and adolescent perspective, and examine the nature of social facilitation between parent and adolescent that contribute to HSM behavior. Forty adolescents with ASD and parent dyads completed the online survey. Guided by the new Adolescent Health Self-

Management (AHSM) Model, results of this descriptive correlational study found many adolescents with ASD were receiving some form of transitional support from parents and report engaging in HSM behavior regardless of receiving guided transition services. However, gaps in health transition may exist during parent and adolescent social facilitation regarding health promoting activities (monitoring health and emotions) and managing existing health conditions (scheduling appointments, managing medications, completing a treatment regiment, etc.). Many conceptual relationships were well explained by the AHSM model in this study. Hierarchical regression analysis found contextual domain variables (parents' marital status, executive function deficits, age at ASD diagnosis) and process domain variables (health knowledge and self-efficacy) explained 43% of the variance in adolescent HSM behavior in this sample. Furthermore, differences in adolescent and parent perspective of beliefs and abilities further reinforce the need for family-centered and coordinated health transition guidance. This is the first known study to examine HSM behavior for adolescents with ASD. Findings of the study suggest many implications addressing practice, research, and policy alike.

Table of Contents

List of Tables

List of Figures

Chapter 1: Introduction

Autism spectrum disorder (ASD) is a neurodevelopmental condition resulting in challenges in social communication and language, restrictive and repetitive patterns of behavior, and speech and nonverbal communication impacting 1 in 54 births in the United States (CDC, 2020; American Psychiatric Association, 2013). However, recent studies point to a more systemic issue regarding ASD not defined by the *Diagnostic and Statistical Manual of Mental Health Disorders*, Fifth Edition. Current research, including studies examining dysregulation of the microbiome, mitochondria, inflammatory, and/or the immune systems, has provided a better understanding of the development of ASD (CDC, 2020; McAllister, 2017; Meltzer & Van de Water, 2017; Vuong & Hsiao, 2017). Considering the vital role these body systems play in health and well-being, it is reasonable that empirical data are now finding that individuals with ASD are at higher risk for almost all physical and mental health conditions when compared to their typically developing peers (Croen, et al., 2015; Cummings, et al., 2016).

Upwards of 95% of individuals with ASD are estimated to have at least one co-occurring health condition in addition to their autism diagnosis (American Psychiatric Association, 2013; Levy, et al., 2010; Soke, Maenner, Christensen, Kurzius-Spencer, & Schieve, 2018). Up to 84% of individuals with ASD report gastrointestinal disorders and a third of this population experiences epilepsy. Mental health conditions such as anxiety (42%), depression (26%), and ADHD (30% to 60%) are relatively common (Autism Speaks, 2017; Croen, et al., 2015; Cummings, et al., 2016; Mannion, Leader, & Healy, 2013). Moreover, about 49% of individuals with ASD have co-occurring intellectual developmental disability or other developmental health conditions such as cerebral palsy and encephalopathy (Autism Speaks, 2017; CDC, 2018; Doshi-

Velez, Ge, & Kohane, 2014; Freeman, Roberts, & Daneman, 2005; Fulceri, et al., 2016; Mannion, Leader, & Healy, 2013; Hsiao, 2014; Rosenfeld, 2015).

The incidence of ASD continues to increase at a significant pace. The most recent report from the CDC (2020) indicates a 10% increase in incidence when comparing 11 surveillance sites between 2014 and 2016 (CDC, 2020). In Texas, the Texas Council on Autism and Pervasive Developmental Disorders (2014) estimated that 399,915 individuals with ASD were living in Texas. Findings of the council indicate that a majority of those diagnosed with ASD in Texas are under 22 years old (Texas Department of Assistive and Rehabilitative Services, 2016). Furthermore, the prevalence of ASD continues to rise steadily and autism is now the fastest growing disability category in the United States (Arehart-Treichel, 2014; CDC, 2018; Cohen, et al., 2011; Kim, et al., 2011; Lajonchere, Jones, Coury, & Perrin, 2012; Venkat, Jauch, Russell, Crist, & Farrell, 2012). This significant increase is not fully understood (e.g., increased awareness, expanded definition of ASD, better treatment/detection, and/or biologic or environmental factors). However, what is known is more than ever individuals with ASD are accessing healthcare services and resources that are unprepared to meet the high demand (Autism Speaks, 2017; Cummings, et al., 2016; Giuseppina & Warfield, 2012; Texas Health and Human Services Commission, 2019).

Co-occurring health conditions are often untreated or undertreated in the ASD population, which leads to poor health outcomes and premature mortality rates (DaWalt, Hong, Greenberg, & Mailick, 2019; Guan & Guohua, 2017; Hirvikoski, et al., 2016). Findings from a large sample, 20-year longitudinal study found that individuals with ASD in the study died 38.5 years prior to their life expectancy relating to health conditions, accidents, and medication side effects (DaWalt, Hong, Greenberg, & Mailick, 2019). The study went on to find that for

individuals with ASD having fair or poor health was the strongest predictor of mortality with a 46% increased risk of dying over the next 20 years when compared to healthy typically developing peers. The heightened risk for and occurrence of health conditions in this population places adolescents with ASD among the over 13.8 million youth with special health care needs (YSHCN) in the United States today (Health Resources & Services Administration, 2018).

Since 1998, the Maternal and Child Health Bureau has defined YSHCN as, "those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally" (McPherson, et al., 1998, p. 138). As YSHCN, adolescents with ASD and their families must manage the adolescent's health condition(s) in addition to the demands of their autism disorder and regularly co-occurring conditions (e.g. executive functioning deficits, sensory hyper/hypo sensitivity, sleep disorders, communication deficits). Previous research of YSHCN in HSM has mostly not included adolescents with ASD. Furthermore, most youth with ASD require services (e.g. psychiatric, occupational therapy, speech therapy) beyond just prescription medication to manage their health condition(s) at a rate twice that of other YSHCN without ASD (Karpur, Lello, Frazier, Dixon, & Shih, 2018). Meeting the lifelong health care needs of the ASD population requires significant support and planning, often in collaboration with multiple specialist and health care providers (Aylott, 2010; Bultas, McMillin, & Zand, 2015; Kuhithau, Warfield, Hurson, Delahaye, & Crossman, 2014; Venkat, Jauch, Russell, Crist, & Farrell, 2012; Dang, et al., 2017).

Health self-management (HSM) behavior beginning in adolescence is an effective strategy to address the increased health care demand and quality of care issues facing YSHCN (American Academy of Pediatrics, 2011; Lozano & Houtrow, 2018; McNaughton, Balandin,

Kennedy, & Sandmel, 2010; NIH, 2013; NINR, 2016). Coordinated condition specific knowledge and beliefs, self-regulation skills and abilities to manage acute, chronic, and preventative health care in a consistent, extended manor defines the essence of HSM. Treatment adherence, building personal autonomy and ownership of one's health condition through the ability to navigate challenges and problem solve, and increase skills and knowledge necessary to manage health conditions throughout one's lifetime are health care outcomes improved through increased HSM behavior (White, et al., 2018). Guidelines proposed by the American Academy of Pediatrics, American Academy of Family Physicians, and American College of Physicians suggest introduction of health care transition to adulthood to all youth by age 12 years within a supported medical home (American Academy of Pediatrics, 2011). Within the guidelines, health transition from adolescence to adult responsibilities is part of a larger theoretical framework based on nine overarching principles: importance of youth/young adult-centered focus; emphasis on self-determination, self-management, and family engagement; acknowledgement of individual complexity; recognition of vulnerabilities; need for early and continuous preparation; importance of shared accountability and communication among providers/support system; recognition of the influence of cultural beliefs, attitudes, and socioeconomic status; emphasis on health equity and disparities; and need for parents to support youth in building knowledge of their own health to make decisions impacting their health (White, et al., 2018). Transition in this dissertation study, refers to the characteristics and premise of these overarching principles.

The medical home model is a patient and family-centered care delivery process focused on preventative care, acute illness management, and chronic condition management (American Academy of Pediatrics, 2011). Care within the medical home model involves planned and proactive care following evidence-based guidelines, written care plans, and active care

coordination with the goal to maximize health outcomes. Transition from adolescence to adulthood in the medical home is considered the gold standard in meeting unmet health care needs for youth transitioning to adulthood and has been associated with comprehensive, coordinated, and family-centered care in primary care settings (Farmer, et al., 2014). A recent update of the 2011 clinical report by the American Academy of Pediatrics states that the tenets and algorithm of the original transition recommendations remain unchanged (White, et al., 2018). Unfortunately, only 18.9% of youth with ASD have access to a medical home network. As a result, it is unclear how the triad (health provider, family, adolescent with ASD) within transition contributes to adolescent with ASD readiness to engage in HSM behavior (Cheak-Zamora, Yang, Farmer, & Clark, 2013).

AUTISM AND FAMILY CENTERED CARE

Family-centered care is a partnership approach to health care decision making between family and health care provider(s) based on information sharing, respecting differences, collaboration, negotiation, and providing care within the context of family and community (Kuo, et al., 2012). In a study utilizing the 2016 National Survey of Children's Health, Karpur (2018) suggests that one component of the medical home model, known as family-centered care, was a statistically significant independent predictor related to unmet health care needs in multivariate models (Karpur, Lello, Frazier, Dixon, & Shih, 2018). Karpur's study using the U.S. Census Bureau for the Maternal and Child Health Bureau database (2018), comparing health care utilization of children with ASD, children with other disabilities, and children without disabilities reported that children with ASD were least likely to receive family-centered care among the three groups. This may be due to a high proportion of children with ASD in the study belonging

to single-parent households, having low-quality health insurance, and experiencing financial hardship (Karpur, Lello, Frazier, Dixon, & Shih, 2018).

Existing research in barriers to health transition has largely focused on the lack of available structured transition programs due to the absence of healthcare providers willing and/or able to transition YSHCN (American Academy of Pediatrics, 2011). Findings from these studies suggest that up to 70% of providers share the perspective of being unprepared, undertrained, and often decompensated when caring for young adults with complex health care needs, especially those with autism (Kuhithau, Warfield, Hurson, Delahaye, & Crossman, 2014; McPheeters, et al., 2014; Warfield, Crossman, Delahaye, Der Weerd, & Kuhlthau, 2015). Beyond reported provider barriers, little is understood about parent's perspective regarding the nature of their child's readiness to engage in HSM behaviors. Studies have, however, explored parent's perspective on their own struggles transitioning their child. Nguyen *et al.* identified in their study exploring the perspectives of adolescents with chronic health conditions, their parents, and healthcare providers that successful transition to adult services was dependent on youth increasing their independence, parents serving as safety nets, and healthcare providers being enablers and collaborators (Nguyen, et al., 2016). The study suggests that a parents' role supporting their child is vital to successful transition in several aspects including the collaborative role they play within and outside of the triad. It has been suggested that a parent's success as a facilitator in their child's health transition is dependent on the parents' ability to redefine their own role from one of control to one of support and guidance (Heath, Farre, & Shaw, 2016). Parents report a significant amount of stress, turmoil, and fear relating to the uncertainty during health transition (Heath, Farre, & Shaw, 2016; Nguyen, et al., 2016; White, et al., 2018). Transition of health responsibility from the parent to the child is not an event, but a

process occurring throughout adolescence. Continued parental involvement provides improved health care outcomes and treatment adherence (Reed-Knight, Blount, & Gilleland, 2014). An adolescent's personal autonomy during this period is a vital part of normal growth and development. Studies indicate that supporting youth in taking responsibility for their own health is not only beneficial for improved health outcomes throughout one's life, but also fosters independence and self-efficacy (Reed-Knight, Blount, & Gilleland, 2014; White, et al., 2018).

Presently, parents of children with ASD are carrying a large amount of the health care burden due to the near absence of structured health transition services and the lack of consistent family-centered care (Farmer, et al., 2014). In addition, parents of youth with ASD are often managing several specialty providers simultaneously complicating the health care burden since communication and collaboration is reportedly poor between providers (Cheak-Zamora, Teti, & First, 2015; Dang, et al., 2017; Farmer, et al., 2014). A burgeoning body of research has focused on the higher levels of stress, anxiety, and depression parents of children with ASD experience compared to parents of children with other special health care needs and typically developing peers (Bekhet, Johnson, & Zauszniewski, 2012; Bonis & Sawin, 2016; Burke, Waitz-Kudla, Rabideau, Taylor, & Hodapp, 2018; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). It has been suggested that parent perception of their child's ability to deal with complex situations relates to parent encouragement of their child in decision making and increased responsibility (Cramm, Strating, Roebroech, & Nieboer, 2013). Therefore, understanding a parents' perspective of their child's self-management abilities and skills may provide valuable insight into the parent's ability to support their child's health autonomy through social facilitation.

AUTISM AND TRANSITION

The World Health Organization defines adolescence as a phase of life between childhood and adulthood (World Health Organization, 2021). While the World Health Organization identifies adolescence as ages 10 to 19 years, this age range has many variations depending on the identifying source. Adolescents in this dissertation study are identified as 12 to 22 years. For adolescents with special health care needs, especially those with ASD, HSM appears to occur along with transition from pediatric to adult provider processes. There is a paucity of research for adolescent HSM separate from transition to adult health studies. Transition service provisions as described by the American Academy of Pediatrics nine overarching principles are often ambiguous, incomplete, and/or introduced too late to properly support an effective transition to adult services (American Academy of Pediatrics, 2011; Betz, et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). The 2016/2017 National Survey of Children and Youth with Special Health Care Needs reported that nationally less than 14.6% of youth ages 12 to 17 years and their families received the services necessary to make appropriate transition to adult health care (US Department of Health and Human Services, 2019). In the state of Texas, less than 13.2% of YSHCN aged 12 to 17 years report to have received appropriate necessary transition services. The lack of theoretical frameworks and interventions necessary to implement the American Academy of Pediatrics' recommendations has been identified as a barrier to promoting transition planning (Betz, et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Also missing are well documented post-transition outcomes to support the American Academy of Pediatrics guidelines (White, et al., 2018).

For adolescents with ASD, the transition to adulthood includes process variables such as health knowledge, self-determination, and self-efficacy that increase responsibility and self-

management abilities of the adolescents' health, but simultaneously recognize contextual variables that may need attention or stabilization before engaging in HSM behavior. A model meeting this need must also recognize the integral role of parents in the HSM process and the adolescents' development that may progress over time to enhance HSM readiness. Based on the social-ecological theory, Schwartz *et al.* (2011) developed one of the only known transition readiness models (SMART transition model) for adolescents and youth transitioning to adult provider services. While the SMART model identifies many of the above-mentioned concepts, it was developed for childhood cancer survivors and not necessarily youth currently experiencing chronic health condition(s). The model chooses to prioritize the process variables, labeled modifiable subjective variables, as suitable targets for intervention and does not embrace the complexity of HSM for families when acute or chronic health conditions are present. Therefore, the SMART model leaves many of these vital factors poorly defined or unaddressed. One such factor left unaddressed in the SMART model is the social facilitation occurring between stakeholders (adolescent, parent, health care provider).

Social facilitation refers to the shared relationship between adolescent and parent to enhance the adolescent's capacity to engage in HSM behavior. Social facilitation includes social influence, social support, and negotiated collaboration that occurs within the parent/child relationship (Reed-Knight, Blount, & Gilleland, 2014; Ryan & Sawin, 2009). In this dissertation study social facilitation refers to what the parent is doing to support and prepare their child to self-manage their own health and what the adolescent is doing to learn how to take care of their health. Understanding the social facilitation between the adolescent with ASD and their parent may provide insight for health care professionals seeking to deliver psychoeducation, intervention, and/or support to families during this vulnerable period of change. Parents of

children with ASD may lack awareness to transition their child to increased health responsibility. Furthermore, they may be absent from parental guidance, monitoring, and support during the transition process which may hinder the adolescent's HSM readiness to engage, and hence HSM behavior (Farmer, et al., 2014; Heath, Farre, & Shaw, 2016; Reed-Knight, Blount, & Gilleland, 2014). Research exploring this phenomenon is limited and when available generally has focused on providers and parents of YSHCN perspective and not the perspective of youth with ASD. The lack of empirical data suggests that adolescents with ASD may not engage in HSM behaviors and/or this phenomenon is not being presently studied. Examining this multifactorial process provides a better understanding of the engagement of the adolescent with ASD, the involvement of family, and their perspective of support provided by health care provider(s) in HSM behaviors.

AUTISM AND ADOLESCENT HEALTH MANAGEMENT

Within the complexity of the transition process, it is the adolescent's beliefs, abilities, knowledge and skills that must be ready to begin taking ownership and responsibility of their own health. Leading self-management researchers identify confidence provided by self-efficacy, autonomous motivation provided by self-determination, ownership of the condition provided by shared decision making, and the skills and abilities necessary to change behavior provided through self-regulation as basic variables necessary to engage in HSM behaviors (Bodenheimer, Lorig, Holman, & Grumback, 2002; Deci & Ryan, 2008; Johnson, et al., 2015; Lorig, 2003; Lorig & Holman, 2003; Ryan & Sawin, 2009). Disease and medication knowledge are believed to support adolescent readiness to engage in HSM behavior and have been identified by adult health providers as highly important for successful transition of YSHCN (Reed-Knight, Blount, & Gilleland, 2014). The specific needs of adolescents with ASD to support engagement in HSM

behavior in managing their health is unknown and may be overlooked when these adolescents are included within existing studies of youth with other special health care conditions. Issues stemming from previous transition studies of YSHCN include poorly defined study samples that may or may not include individuals with ASD, absent or small sample sizes (if ASD is identified in the sample), and/or often represent the perspective of parents and/or providers only (Johnson, et al., 2015; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Tesfaye, et al., 2019). Innovative studies from the perspective of adults with ASD have voiced both motivation and desire to engage in HSM behavior (Nicolaidis, et al., 2015; Nicolaidis, et al., 2012). These studies used adaptive survey instruments to assess the needs of a large sample of adults with ASD having varying levels of experience and abilities across 47 states in the United States. Regrettably, these types of studies have not been conducted with adolescents with ASD and their motivation and desire to engage in HSM behavior remains unknown.

Effective HSM interventions for adolescents with ASD include self-monitoring, goal setting, and self-evaluation (Aljadeff-Abergel, et al., 2015; Carr, Moore, & Anderson, 2014; National Autism Center: A center of May Institute, 2015). Subsequently, numerous studies exploring self-efficacy, self-determination, autonomous goal setting abilities and adaptive devices that support independence of adolescents with ASD are beginning to appear in the literature (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2017; Hume, Loftin, & Lantz, 2009; Johnson, et al., 2015; McNaughton, Balandin, Kennedy, & Sandmel, 2010; Odom, et al., 2015). One study examining psychosocial health specifically compared interpersonal efficacy of adolescents with ASD (n=22), their parents, and typically developing peers (Locke & Mitchell, 2016) found that parents of adolescents with ASD lacked confidence in their child's interpersonal skills, especially to connect and lead others. Despite the parent's lack of confidence

in their child's interpersonal skills, adolescents with ASD and their neurotypical peers had similar levels of efficaciousness, child-parent agreement, and meta-perception (child's perception of parent's perception or parent's perception of child's perception) accuracy regarding the adolescent's strengths/weaknesses. The implications of this study suggest that parents of adolescents with ASD and providers could use the agreement in adolescent and parent self-perceptions regarding strengths/weaknesses as a guide for intervention during transition to adulthood. Currently, no known studies have been conducted that specifically address the knowledge, beliefs, skills, or abilities of adolescents with ASD in HSM behavior or the nature of social facilitation between these adolescents and parents that may impact HSM behavior.

It is well established that contextual variables (adolescent condition, environment, individual/family characteristics) and process variables (knowledge, beliefs, skills, abilities) that support the adolescent within a structured transition program lead to successful shift in responsibility and HSM behavior in adolescents with other special health care needs (Bauman, Kuhle, Bruce, Bolster, & Massicotte, 2016; Cole, Ashok, Razack, Azaz, & Sebastiam, 2015; Lozano & Houtrow, 2018; McNaughton, Balandin, Kennedy, & Sandmel, 2010; Sawin, Bellin, Roux, Buran, & Brei, 2009; Verchota & Sawin, 2016; Warchausky, Kaufman, Schutt, Evitts, & Hurvitz, 2017). However, due to the lack of available research with adolescents with ASD, especially from their own perspective, it is unclear how contextual variables (e.g. complexity of health condition, complexity of autism, ability to self-manage, as well as demographic characteristics) and variables in the process domain that contribute to developing HSM behavior (e.g. self-efficacy, self-determination, condition specific knowledge, ability to communicate with provider, planning ability, and HSM readiness) may relate to the adolescents' ability to engage in HSM behavior (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Griffin, Taylor, Urbano, &

Hodapp, 2014; Hume, et al., 2017; Reed-Knight, Blount, & Gilleland, 2014; Lajonchere, Jones, Coury, & Perrin, 2012; Venkat, Jauch, Russell, Crist, & Farrell, 2012). Therefore, a better understanding of this multifaceted HSM phenomenon will help guide future interventions and resource systems aimed at supporting HSM in adolescents with ASD (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011).

STATEMENT OF PURPOSE

The purpose of this cross-sectional descriptive correlational research study is to 1) explore the relationship by which contextual variables (capacity to self-manage, complexity of condition, demographic aspects, access to family centered care) and process variables (health knowledge, self-efficacy, self-determination, communication with provider, HSM readiness) relate to HSM behavior, 2) compare adolescent and parent perspective of the adolescent's HSM behavior, and 3) examine the nature of social facilitation between adolescent with ASD and their parent to enhance the adolescents' HSM behavior.

RATIONALE AND SIGNIFICANCE

Investigating HSM in adolescents with ASD is significant because they are medically complex, with most individuals with ASD (up to 95%) having a comorbid condition of either a physical, mental, and/or developmental health disorder(s) (Levy, et al., 2010; Soke, Maenner, Christensen, Kurzius-Spencer, & Schieve, 2018). People with ASD have poor health outcomes and premature mortality rates (Cummings, et al., 2016; DaWalt, Hong, Greenberg, & Mailick, 2019; Guan & Guohua, 2017; Hirvikoski, et al., 2016). This study aims to address this health disparity because it: 1) addresses a health care need experienced by adolescents with ASD and their families; 2) examines ASD knowledge, beliefs, abilities, and skills of adolescents from their own perspective and how these variables relate to their HSM; 3) explores the concepts and

propositions to engaging in HSM behaviors in this population and provides first steps to understanding this complex phenomenon.

Findings from this exploratory study have implications for practice, research, and healthcare policy for health care transition processes and family-centered care. The Adolescent Health Self-Management Model used to guide this study may provide guidance for interventions and resources not currently identified in the literature. The study provides insight for future research addressing improved health care outcomes in an increasing, high risk population.

THEORETICAL FRAMEWORK

The conceptual framework for this study is the Adolescent Health Self-Management Model, the conceptual framework presented here provides a comprehensive view of HSM for adolescents with ASD (Rock & Becker, 2021). The model was informed by the Individual and Family Self-Management Theory (Ryan & Sawin, 2009), the Transition Theory (Meleis, Sawer, Im, Messias, & Schumacher, 2000), Developmental Contextualism (Lerner R. M., 1992), and the Transtheoretical Model (Prochaska & Velicer, 1997). The contribution of each theory and model is discussed below.

Individual and Family Self-Management Theory

The Individual and Family Self-Management Theory provided many of the critical components of self-management guiding this study. Founded on the perspective of family systems theory, the Individual and Family Self-Management Theory states that change in one element of a structure (family member) leads to change in the structure (family) and all its members (Ryan & Sawin, 2009). This perspective is shared by the theory of developmental contextualism, a fundamental psychosocial theory providing insights into human development across the life span (Lerner & Miller, 1993). Developmental contextualism relates adolescent

development to family, peers, school, and community concepts in reciprocal relationships where not only is the adolescent influenced by these concepts, but the adolescent concurrently shapes the concepts (Lerner R. M., 1992; Lerner & Miller, 1993). Future studies may examine other environmental influences and supports (peers, school, community) that may influence adolescent development of HSM behaviors, but this dissertation study examines the parent relationship relating to social facilitation. Plasticity is a major concept defined in developmental contextualism as the relative flexibility or capacity to change behavior to meet contextual demands (Lerner & Hood, 1986). Together, these concepts provide insight into adolescent growth and behavior while interacting with their environment and further support the Individual and Family Self-Management Theory conclusion that outcomes improve when both the individual and family perspective is addressed (Ryan & Sawin, 2009). In the Individual and Family Self-Management Theory, focus is on the individual, the dyads within the family, and the family as one unit that move through four distinct domains in the development of self-management behaviors. In Ryan and Sawin's self-management theory, the contextual domain contains risk and protective factors within subcategories including condition specific (e.g. complexity of condition, complexity of treatment), physical & social environment (e.g. access to health care, provider transitions, culture), and individual & family factors (e.g. developmental stage, literacy, demographic/socioeconomic factors). Contextual domain characteristics directly or indirectly impact the amount, type, and nature of actions needed to self-manage (Ryan & Sawin, 2009). In that theory, the contextual domain connects to the process domain of self-management.

The process domain of the Individual and Family Self-Management Theory is influenced by health behavior change, self-regulation and social support theories. The process domain

includes potentially modifiable variables contributing to knowledge, beliefs, skills, abilities, and social facilitation necessary to engage in self-management behavior. The key components of the process domain include knowledge & beliefs (self-efficacy, goal congruence, and outcome expectancy), self-regulation skills & abilities (goal setting, reflective thinking, self-evaluation, decision making), and social facilitation (influence, support, and collaboration). The process domain in turn connects to the proximal, or short-term results, outcome domain (e.g. self-management behaviors, use of appropriate health care services), which then connects to the distal, or long-term results, outcome domain (e.g. health status, quality of life, and cost of health). Ryan and Sawin (2009) challenge traditional self-management theories presenting family as a separate entity and have integrated the individual and family as one multidimensional unit. The authors believe this approach reflects the reality of daily living with a chronic illness for families and emphasize the significant role parents play in the process of adolescent self-management.

Transition Theory

The transition theory was developed by Meleis and fellow researchers to define and create the process of transition when caring for patients. Described as a central concept of nursing, transitions result from changes in health, relationships, environments, and life (Meleis, Sawer, Im, Messias, & Schumacher, 2000). Thus, developmental transitions such as adolescence to adulthood and health/illness transitions that require taking ownership and increased responsibility for one's health condition are described by Meleis as vulnerable periods of time when individuals are at higher risk for harmful illness, problematic recovery, and/or delayed or unhealthy coping. Meleis et al. (2009) explored the diversity and complexity of research findings from five transition studies and discerned (or identified) themes that now represent the transition

theory. The researchers report the nature of transitions as consisting of types (situational, developmental, organizational, health/illness), patterns (single, multiple, related, unrelated sequential, simultaneous), and properties (awareness, engagement, transition time span, change & difference, critical points & events) that impact facilitators and inhibitors of the transition process that ultimately lead to mastery of the process or need for additional health care support.

The transition theory provides a necessary framework for understanding transition to guide proper nursing intervention and support as clients move through the transition experience. It is the nature of transition subcategories provided by Meleis's theory that deliver insight and clarity to the new Adolescent Health Self-Management Model by identifying the types, patterns, and properties of transition from pediatric to adult provider experienced by adolescents with ASD and their parents. For example, there are several transitions taking place simultaneously within this phenomenon: adolescent to adulthood (developmental), adolescent as owner of health care condition (illness/health), and the parent changing role from one of responsibility to support (developmental/situational). Thus, the adolescent and/or parent may need additional support or intervention during this process. Moreover, Meleis proposes that without a properly trained health care provider to guide the transition process, factors of the transition such as awareness and engagement of the child and family in HSM may not occur at all (Meleis, Sawer, Im, Messias, & Schumacher, 2000).

Transtheoretical Model

The transtheoretical model of health behavior change posits that readiness to engage in change progresses through five distinct stages over time: precontemplation, contemplation, preparation, action, and maintenance. An individual can also relapse or regress to an earlier stage of readiness as well. The time that an individual spends in each stage varies, however, the tasks

needed to progress beyond each stage is invariant based on change processes and relational stances. Using principal components analysis, Prochaska, DiClamente, and Velicer, developed a scale to assess participants conscious motivation to change via measurement of their positive or negative thought processes (pros and cons) relating to the proposed behavior change (Norcross, Krebs, & Prochaska, 2011; Prochaska J. O., 2008). Prochaska called this weighing of pros and cons a decisional balance. The participant's stage of readiness toward the proposed behavior change predicts the extent of the participant's decisional balance regarding the proposed behavior change.

Precontemplation is the stage when individuals are not intending to act in the foreseeable future (usually not within the next six months). Lack of awareness or under awareness of the issue needing change is generally seen during this stage. Con perspective significantly outweighs pro perspective during this stage. Contemplation is the stage when an individual considers a change and intends action in the next six months. Con perspective still outweighs pro perspective at this time, but pro perspective has increased. Preparation is the stage when an individual intends to act on the change soon via a developed plan, usually within the next month. Pro perspectives continue to increase, and con perspectives have lessened during this time. Action stage is when a modifiable behavior change is observed in the individual reaching a threshold that reduces health risk. Occurring sometime in the last six months, this active behavior change is accompanied with the highest pro perspective. Maintenance is the last stage. During this time, usually post six months of action stage, the individual is working to prevent relapse to an earlier stage of change. Self-efficacy in the form of increased confidence regarding the health behavior change is experienced during this stage. Relapse to an earlier stage results in regression, which may suggest need for additional support. Individuals remain in one of the five stages throughout

life as long as the health behavior is needed. For adolescents with ASD, understanding where they are in their stage of readiness toward engagement of HSM provides insight for parents and providers to increase support of pro factors or decrease con factors allowing the adolescent to progress to the next stage of readiness.

Adolescent Health Self-Management Model

In the Adolescent Health Self-Management Model (see Figure 1A), contextual and process factors have a linear relationship. HSM readiness, within the process domain, is a fundamental concept that pulls all the process factors together into one common progressive goal, engaging in HSM behavior. HSM readiness provides a way of gauging health change behavior. In other words, as the adolescent's knowledge, beliefs, skills, and social facilitation increase the adolescent reaches a higher stage of readiness. Reaching a higher state of readiness increases the adolescent's state of being prepared and willingness to engage in HSM behaviors. Equally integrated into the process domain, social facilitation involves the parent "letting go" or handing off at least some responsibility of the health condition and the child engaging in learning how to self-manage their health by increasing knowledge, skills, abilities, and/or belief in taking responsibility for their health care. Both parent and adolescent social facilitation events must occur before the adolescent is ready to move toward engaging in HSM behaviors. Therefore, social facilitation also goes through stages of readiness. Additionally, studies indicate that continued parental involvement and monitoring during the healthcare transition phase are seen as key factors in positive health outcomes and improved medication adherence, especially for adolescents with special health care needs who may experience a prolonged health care transition (Reed-Knight, Blount, & Gilleland, 2014). Therefore, continued social facilitation between adolescent and parent is recommended as a part of the adolescent's HSM behavior until the

adolescent reaches adulthood and/or complete independence is reached. The role of the healthcare provider is to guide and support the individual and family undergoing social facilitation while developing HSM behavior. The healthcare provider, along with other members of the health care team, will assess and support adolescent and parent contextual and process factors in a family-centered care setting.

As previously discussed, HSM for adolescents with ASD often occurs within the transition to adult healthcare. It is understood that there may be many types of transition co-occurring for adolescents during this time. The characteristics of transition type, pattern, and property may need recognition and intervention support if individuals struggle with anxiety, fear, and/or psychological strife relating to the uncertainty of change, especially when health well-being is at stake. Indeed, adolescent psychological health, both internalizing and externalizing behaviors, has been shown to relate to transition success (Reed-Knight, Blount, & Gilleland, 2014) and occurrence of depression for YSHCN has been well established (Gerson, Furth, Neu, & Fivush, 2004; Gray, Denson, Baldassano, & Hommel, 2012; Mattson & Kuo, 2019). According to the 2016 National Survey of Children's Health, 42.4% of YSHCN report having a co-occurring emotional, developmental, or behavioral issue (Mattson & Kuo, 2019). Behavioral health can strongly impact physical health and wellness outcomes for YSHCN. An illustration of a developmental issue impacting adolescents with ASD may be the experience of "good days" and "bad days" when previously established skills and abilities become more challenging. Recognizing and supporting these challenges, as well as cognitive and communication deficits when present in this population may require added guidance and referral to appropriate training services. The cognitive functioning variable executive functioning is one such example.

Executive functioning characteristics include inhibition, working memory, cognitive flexibility, and planning. When executive function problems exist, deficits in cognitive skill may serve as a barrier to managing complex health care conditions. Numerous studies have examined executive functioning deficits in children, adolescents, and adults with ASD and have found that some, but not all individuals on the spectrum experience clinically significant executive functioning deficits. Given the planning, organizing, problem solving, self-monitoring, and working memory necessary to self-manage one's health, deficits in one or more of the executive functioning domains may require additional environment and regimen modifications. It should be noted that advances in technology and the development of cognitive remediation training programs for individuals with executive functioning deficits have provided adaptive tools and supports for successful health care related tasks despite these cognitive difficulties (Hume, Loftin, & Lantz, 2009; Odom, et al., 2015; Reed-Knight, Blount, & Gilleland, 2014). With the added involution of both ASD and co-occurring health condition(s), proper assessment and support of executive functioning deficits is necessary to assure proper interventions are in place.

Regardless of an individual's disability, communication exchange between health care provider and patient is essential. Therefore, strategies to support the communication differences accompanying ASD that are based on the individuals needs and abilities can include the use of a health passport or diary kept by the adolescent to recap current health status, previously discussed topics, and changes observed since last visit (McNaughton, Balandin, Kennedy, & Sandmel, 2010). How to develop the health passport and what is included should be part of the HSM process between adolescent, parent, and health care provider. The health passport can track previously learned knowledge, skills and abilities needing recurrent assessment and monitoring to assure successful behavior change. Hence, a change in contextual factor or regression to an

earlier stage of readiness may impede the adolescent's ability to self-manage their health and require them to relearn process factors or gain new motivation. Therefore, a health passport or diary would provide on ongoing form of communication for assessing current health status and readiness stage through a supportive tracking device. While the first three stages (precontemplation, contemplation, preparation) of HSM readiness represent the non-engaging aspects of HSM behavior and the last two stages (action, maintenance) represent the engaging aspects of HSM behavior, all five stages reflect the progress of health change taking place over time as the adolescent engages in HSM behavior.

Process domain factors are believed to relate to proximal domain outcomes that include consistent engagement in HSM behaviors, ownership of health status, and increased use of appropriate healthcare services. Proximal domain outcomes relate to distal domain outcomes that include heightened health status, improved quality of life, and personal autonomy. Lastly, the concept of time is shown to relate to all domain factors and represents changes over time (history) that occur throughout the adolescent's development. While ASD is a lifelong disorder, significant growth and development typically takes place during adolescence as the youth begins to develop independence and autonomy from their parent(s). According to developmental contextualism theory time also represents the experiences (history) that make the adolescent unique (Lerner & Miller, 1993). Lerner (1993) states, "a person's unique history of experiences and roles, as well as his or her unique biological (e.g., genetic) characteristics (McClearn, 1981), combine to make him or her unique; with time, and given the accumulation of the influences of distinct roles and experiences, the person becomes increasingly unique over the course of life" (p. 353).

It is through the synthesis of the Individual and Family Self-Management Theory, transition theory, developmental contextualism and transtheoretical models, in conjunction with a thorough review of the literature (Chapter 2) addressing the health of the adolescent with ASD,

***Figure 1A*. Adolescent Health Self-Management Model[1]**

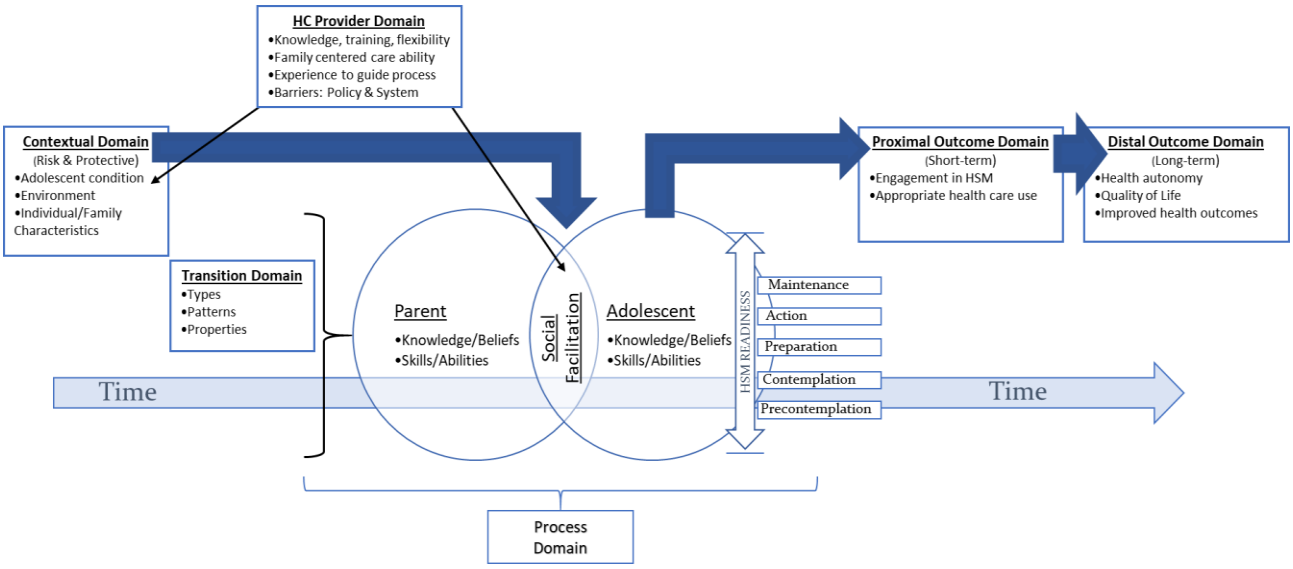
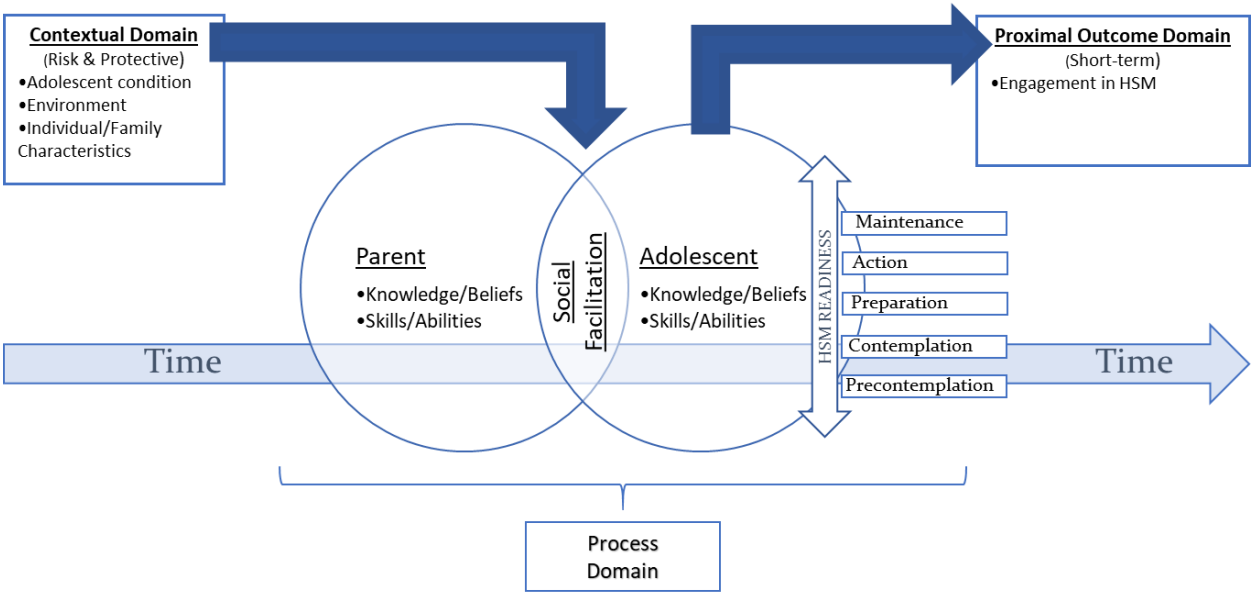


Figure 1B. Model Aspects Addressed in Dissertation Study



[1] Adolescent Health Self-Management Model published (Rock & Becker, 2021)

that a new conceptual framework was developed. While the new Adolescent Health Self-Management Model addresses the complexity of the multifaceted adolescent HSM phenomenon (see Figure 1A), this study specifically addressed variables in the contextual domain and process domain relating to HSM behaviors in adolescents with ASD (see Figure 1B). The role of the provider, transition factors, certain contextual factors (access to adaptive resources, social and family supports), certain proximal outcomes (appropriate use of health care), and distal outcomes were not addressed in this exploratory study.

STUDY AIMS AND RESEARCH QUESTIONS

Specific Aim 1: Explore what factors are associated with HSM among adolescents (age 12-22 years) with ASD

Rationale: Despite the importance of health self-management, self-management's role in the ASD population is not well understood. Specific Aim 1 takes first steps in examining relationships of key contextual and process variables to enhance the engagement of adolescents with ASD in HSM behavior. In keeping with another study measuring HSM behavior in adolescents with Type 1 diabetes (Verchota & Sawin, 2016), this study sought to further understand HSM in adolescents with ASD. This study also examined contextual and process domain variables to identify how these constructs relate to the Adolescent Health Self-Management Model. The following research questions addressed specific Aim 1:

RQ 1.1: How do adolescents with ASD and their parent rate the adolescent's engagement in HSM behavior?

RQ 1.2: What are the bivariate relationships among the contextual variables (adolescents' health care condition, complexity of ASD, executive function deficits, depressive symptoms, access to family-centered care, age, SES, gender, race, ethnicity) and process variables (health knowledge, health communication/planning, self-efficacy, self-determination, HSM readiness) and the adolescent and parent rating of the dependent variable adolescents' HSM behavior?

RQ 1.3: How much do adolescent's health knowledge, health communication/planning, self-efficacy, self-determination, and HSM readiness explain the variance in adolescent's HSM behavior after controlling for individual and family contextual factors (access to family-centered care, SES, gender, age, race, ethnicity, complexity of ASD, complexity of health condition, executive function deficits, and depressive symptoms)?

Specific Aim 2: Compare adolescent with ASD and parent perspective of HSM behavior

Rationale: Studies of other types of transition suggest discrepancies between adolescent with ASD and parent ratings on measures and differences in priorities during the transition process (Hodgetts, Richards, & Park, 2017; Hume, et al., 2017; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). Therefore, Specific Aim 2 seeks to better understand differences between adolescent and parent perspective of contextual and process domain variables. The following research question addressed Specific Aim 2:

RQ 2.1: How do adolescent and parent perceptions of the adolescents' contextual and process variables (depressive symptoms, health knowledge, health communication/planning, self-efficacy, self-determination) and HSM behavior compare?

Specific Aim 3: Examine the nature of social facilitation between adolescents with ASD and their parents to enhance adolescents' HSM behavior

Rationale: Current research suggests that parents play a vital role in the transition of increased health care responsibility in adolescents with special health care needs (American Academy of Pediatrics, 2011; Reed-Knight, Blount, & Gilleland, 2014). However, it is unknown how or if adolescents with ASD gain the necessary knowledge, skills, and abilities to acquire the increased responsibility from their parents in managing their own health. Studies addressing the challenges faced by individuals with ASD and their families in managing the youths' health suggest contextual variables may significantly impact typical family functioning and development (Berg, Shiu, Feinstein, Msalll, & Acharya, 2018; Bordonada, 2017; Farmer, et al., 2014; Hall, Kriz, Duvall, Nguyen-Driver, & Duffield, 2015; Hock, Kinsman, & Ortaglia, 2015). Therefore, Specific Aim 3 sought to better understand the process of social facilitation between the adolescent with ASD and their parent to develop the adolescent's readiness to care for their own health. The following research questions addressed specific aim 3:

RQ 3.1: What do parents do to prepare their child to transition to HSM behavior?

RQ 3.2: What are adolescents with ASD doing to transition to self-manage their health?

RQ 3.3: What do parents perceive as barriers to transitioning their adolescent with ASD to HSM behavior?

DEFINITION OF KEY TERMINOLOGY

The following definitions will be used throughout the proposed study:

Adolescent with ASD

An adolescent with ASD, age 12 to 22 years, and identified by parent or primary caregiver as being diagnosed by a professional to meet autism spectrum disorder criteria in

accordance with the *DSM-5* (challenges with social skills, repetitive behaviors, speech and nonverbal communication deficits). With the release of the DSM-V in 2013, ASD became the umbrella term for autism. Prior to that time, the DSM-IV labeled different categories of autism as Autistic Disorder, Pervasive Developmental Disorder-NOS, and Asperger's Disorder. Therefore, individuals previously diagnosed with these disorders are considered as having ASD in the proposed study. In accordance with the American Academy of Pediatric guidelines, all youth beginning at age 12 years should be introduced to HSM and begin transition planning by age 14. Accordingly, YSHCN are to spend the period between 12 to 14 years of age preparing for transition readiness (American Academy of Pediatrics, 2011, p. 190). Therefore, to incorporate all youth having some exposure to self-management planning according to the American Academy of Pediatric guidelines, the lower range of adolescence for this study was originally set at 14 years.

The guidelines also identify youth as ideally completing health transition to adult services between the ages of 18 to 21 years. However, YSHCN are often delayed in transition from pediatric to adult health care providers and may continue to see a pediatrician well after the age of 21 years (Fortuna, Halterman, Pulcino, & Robbins, 2012; Oswald, et al., 2013). Therefore, the upper range of older adolescence in this study was identified using the Texas Department of Assistive and Rehabilitative Services study (2016) and based on the age at which an adolescent is no longer eligible for public school services at age 22 years. Operationally: The study sought 14 to 22-year-old adolescents with ASD, reaching a 6^{th} grade level or above (to assure age-related developmental readiness and ability to understand study demands), and able to read and write in English. Adolescents were required to have an existing diagnosis of ASD at the time of

recruitment into the study based on parent report. Both genders and all racial/ethnic groups were recruited.

Parent of Adolescent with ASD

Operationally: The parental unit or acting parental unit is the mother, father, grandmother, grandfather, or family member acting as the primary caregiver for the adolescent with ASD (14 to 22 years) and able to read and write in English.

Youth with Special Health Care Needs

Conceptually: Defined by the Maternal and Child Health Bureau, YSHCN are individuals who have or are at increased risk for chronic health conditions and require health services in a type or amount exceeding their typically developing peers (McPherson, et al., 1998). Operationally: Many adolescents with ASD are identified as YSHCN. In this dissertation study, adolescents with ASD are identified as YSHCN by answering "yes" on all three parts of at least one question (or two parts on question 5) on the Children with Special Health Care Needs Assessment tool (Appendix H).

Contextual Factors

Conceptually: In alignment with the Individual and Family Self-Management Theory, contextual factors are considered risk and protective factors for individual and/or family that may impact adolescent's engagement in HSM behaviors (Ryan & Sawin, 2009). Operationally: Complexity of ASD will be measured using the AQ-10 (adolescent version) completed by parent (Allison, Auyeung, & Baron-Cohen, 2012). Adolescent depressive symptoms will be measured using the PROMIS Emotional Distress-Depression-Peds Short Form for adolescent perspective and PROMIS-Depression-Parent/Guardian of Child Age 6-17-Short Form for parent perspective. Complexity of adolescent's health condition will be assessed by the number of affirmative answers on the Children with Special Health Care Needs Assessment tool via parent report

(Appendix H) in conjunction with criteria asked on the Background Information Questionnaire (number of co-occurring health conditions - complexity increases with the number of co-occurring health conditions, and amount of time affected by health condition - more hours affected by health care condition, the more complex the co-occurring health care condition). Descriptive statistics will be used to measure the demographic data gathered from the Background Information Questionnaire (Appendix B) including access to family-centered care, type of health insurance, race, ethnicity, and SES.

Executive Function Deficits

Conceptually: Executive function is a set of cognitive processes associated with managing oneself and one's resources in order to achieve a goal. In this study, executive function is a contextual domain factor measuring the learning and cognitive ability of the adolescent with ASD. It is understood that executive function is not the only variable identifying learning and cognitive ability in this population. However, research has suggested that executive function deficits occur throughout the lifetime for some individuals on the autism spectrum (Chen, et al., 2016; van den Bergh, Scheeren, Begeer, Koot, & Geurts, 2014). Executive function refers to the neurologically based skills involving self-regulation and mental control included in four domains: inhibition, working memory, cognitive flexibility, and planning (Reed-Knight, Blount, & Gilleland, 2014). Operationally: Executive function deficits will be measured by Barkley Deficits in Executive Functioning Scale – Children and Adolescents − Short Form completed by parents.

Process Factors

Conceptually: Process factors are inspired by the Individual and Family Self-Management Theory and founded in health behavior change theory, self-regulation theory, and

social support theory. Process factors are the beliefs, actions, skills, abilities and social/emotional supports necessary for the adolescent's engagement in health behaviors (Ryan & Sawin, 2009). The process factors represent the behaviors and actions the adolescent and family members take in increasing their readiness for the adolescent to engage in HSM behavior. Process variables are key to increasing the adolescents' readiness in learning responsibility for their health, which then leads to engaging in HSM behavior. Operationally: Each defined individually (health knowledge, health communication/planning, self-efficacy, self-determination, HSM readiness, social facilitation) below.

Health Knowledge

Conceptually: Health knowledge is factual information (e.g. recognizing signs and symptoms of condition, managing symptoms of condition, medication management) about a health condition or health behavior and is critical to the success of self-management ability (Ryan & Sawin, 2009). According to the Integrated Theory of Health Behavior Change, implementation of interventions incorporating condition specific knowledge and health beliefs is crucial to successful health behavior change (Ryan P. , 2009). It is understood that knowledge alone does not lead to behavior change. However, enhancement of health knowledge in conjunction with supported health beliefs, like self-efficacy, goal congruence, and outcome expectancy are linked to increased levels of self-confidence and engagement in self-regulation behaviors (Ryan & Sawin, 2009). Operationally: Knowledge in this study will be operationalized using a subsection of the $Star_x$ Health Care Transition Readiness Questionnaire completed by both the adolescent (adolescent version) and their parent (parent version, $Star_x$-P). Outcome expectancy and goal congruence will not be addressed in the proposed study.

Health Communication/Planning

Conceptually: Health communication/planning consists of the self-regulation skills and abilities (goal setting, decision making, self-monitoring, planning, self-evaluation, and/or management of responses) an individual applies in the course of health behavior change (Ryan & Sawin, 2009). Operationally: This concept will be measured using a subsection of the $Star_x$ – Health Care Transition Readiness Questionnaire for youth with chronic health condition for the adolescent's perspective of provider communication and planning ability. Additionally, parents will complete the $Star_x$-P – Health Care Transition Readiness Questionnaire for parent of youth with chronic health condition for parent perspective of adolescent's skills and abilities regarding provider communication and planning. Many of these skills and abilities, especially decision making, are linked to self-determination.

Self-efficacy

Conceptually: Self-efficacy is an individual's belief that they can achieve or execute behaviors necessary to attain a goal or action. Self-efficacy is the adolescent's perception of their ability to influence the environment, health behaviors, and health outcomes (Reed-Knight, Blount, & Gilleland, 2014). It is their confidence in their HSM abilities and skills. Operationally: Self-efficacy in this study was measured by the General Self-Efficacy Scale, which is not specific to HSM capabilities. Adolescents and their parents will complete the appropriate version assessing the adolescent's self-efficacy.

Self-determination

Conceptually: Self-determination is the capacity and opportunity a person holds to control their own life or make decisions. According to self-determination theory, self-determination encompasses basic issues such as self-regulation, personality development,

universal psychological needs, energy and vitality, life goals and aspirations, behavior, and well-being (Deci & Ryan, 2008). Operationally: Self-determination in this study was measured using the AIR Self-Determination Scale. The student version will be used for adolescent perspective and parents will complete the version for parent perspective about the adolescent's self-determination.

Social Facilitation

Conceptually: Social facilitation includes the emotional, instrumental, and/or informational influences and supports that help the individual engage in HSM behaviors (Ryan & Sawin, 2009). In this study, it is what the parent is doing to support and prepare their child to self-manage their own health. It is also what the adolescent is doing to learn how to self-manage their health. There are three aspects of social facilitation to consider: social influence, social support, and negotiated collaboration, in which all perspectives are respected and considered influential. Negotiated collaboration takes place when both child and parent roles are mutually meaningful in the development of goals and treatments. Social facilitation between the adolescent and their parent enhances the individual's HSM readiness while increasing in duration, consistency, or intensity. In the Adolescent Health Self-Management Model, increased social facilitation relates to increased HSM readiness. Operationally: This concept was measured using questions addressed individually to both the adolescent and parent (Adolescent question: *What does your parent do to help you learn how to manage your health?* Parent question: *What do you do to help your child learn how to self-manage their health?*). A drop-down menu provided commonly known selections to choose from with an optional free-text option for fill-in or elaboration. A descriptive analysis was used evaluate open-ended data provided by the adolescent and/or their parent.

HSM Readiness

Conceptually: HSM readiness is a state of being fully prepared and willing to self-manage health. Operationally: The adolescent's HSM readiness was measured using the adapted Stages of Change-Short form. The decisional balance (weighing of pro and cons) was assumed based on adolescents' reported stage of readiness (Prochaska J. O., 2008).

Transition Factors

Conceptually: Transition factors are the characteristics of the experienced transition that include transition types (health/illness, organizational, developmental, situational), patterns (related, unrelated, single, multiple, sequential, simultaneous), and properties (change or difference, awareness, engagement) that may require additional support and/or intervention. In the Adolescent Health Self-Management Model, these factors affect the individual's ability to engage in process factors (Meleis, Sawer, Im, Messias, & Schumacher, 2000). Operationally: Transition factors were not measured in this study.

Transition

Conceptually: Transition in this dissertation study is based on many of the overarching principles of health care transition identified by the American Academy of Pediatrics clinical report (2018). The specific principles of health transition in the clinical report relating to this study include processes that: are youth and/or young adult-centered; are family engaged where self-determination and self-management are emphasized; recognize individual differences and complexities; acknowledge distinct health population approach; provide early and consistent preparation into health responsibilities; recognize socioeconomic, cultural, and belief influence; emphasize optimum health outcomes; and recognize the need for parent support in building youth knowledge regarding their own health and skills to make health care decisions (White, et

al., 2018). The American Academy of Pediatrics recommendations supports introduction of health transition beginning at age 12 and suggests youth should participate in the transition-planning process supported by family and healthcare provider (American Academy of Pediatrics, 2011; McManus, et al., 2015; White, et al., 2018). Operationally: Structured transition to adult services was not addressed in this study.

Proximal Outcomes

Conceptually: Proximal outcomes are short-term achievements, activities, and behaviors that support the attainment of distal outcomes, which are long-term achievements. Operationally: Engagement in HSM behavior, as discussed above, is a proximal outcome and the dependent variable in this study. Other proximal outcomes, such as appropriate health care use, were not studied in this exploratory study.

Health Self-management (HSM) Behavior

Conceptually: HSM behavior is a proximal outcome variable reflecting the implementation of health knowledge, health communication/planning, self-efficacy, self-determination used to manage acute, chronic, and preventative health care. Engagement in HSM occurs when adolescents reach a state of actively participating and taking responsibility in the management of acute and chronic conditions or promoting healthy behaviors by decisively performing learned behaviors (Ryan & Sawin, 2009). HSM behaviors in this study reflect consistent HSM behavior for a period of at least three months. While there are commonalities in **general HSM** behaviors among all YSHCN, there are also **condition specific HSM** and adaptive behaviors that must be considered when addressing the needs of the ASD adolescent and their family. Researchers have found that by utilizing both general and condition specific HSM behavior measures they are better informed to optimize the needs of the study population

(Cheak-Zamora, Yang, Farmer, & Clark, 2013; Karpur, Lello, Frazier, Dixon, & Shih, 2018; Reed-Knight, Blount, & Gilleland, 2014; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Ryan & Sawin, 2009; Warchausky, Kaufman, Schutt, Evitts, & Hurvitz, 2017). Therefore, both the general (YSHCN) and specific (YSHCN and ASD) HSM are addressed throughout this study. Operationally: HSM behavior will be measured using a subsection of the $Star_x$ – Health Care Transition Readiness Questionnaire for youth with chronic health condition for the adolescent's perspective. This is a general condition measure as there are no known ASD condition specific measures for HSM behavior. This scale includes items about HSM behaviors including questions such as: How often did you take your medicines on your own?; How often did you make your own appointment?; How often did you make an effort to understand what your doctor told you? Additionally, parents will complete the $Star_x$-P – Health Care Transition Readiness Questionnaire for parent of youth with chronic health condition for parent perspective.

Distal Outcomes

Conceptually: Distal outcomes are long-term outcomes relating to proximal outcomes. Distal outcomes include ownership of health status, quality of life, personal autonomy, and perceived well-being. Also included in distal outcomes are direct and indirect health costs. Operationally: Distal outcomes were not measured in this exploratory study.

RESEARCHER ASSUMPTIONS

Assumptions:

1. Adolescent with ASD were capable of effectively self-examining and accurately conveying health related concerns.
2. Participants in the study were able to understand the questions in instruments utilized to measure the variables of the study and responded honestly and accurately.

3. Adolescents with ASD were motivated to learn HSM skills.
4. Adolescents with ASD and their families engaged in behaviors for reasons that may or may not directly relate to improving their health status.
5. The social and communication deficits seen in ASD can be managed with adaptive support and training.
6. Complex factors affect an individual and family's ability and desire to self-manage adolescents' health.
7. Health status is meaningful to individuals on the spectrum and their families.
8. Models, measures, and literature based on other YSHCN also apply to youth with ASD.

SUMMARY AND ORGANIZATION OF THE DISSERTATION

Most adolescents with ASD experience health comorbidities placing them at increased risk for unmet health care needs that may lead to early mortality rates in this population. Benefits of HSM by individuals caring for their acute and chronic health condition(s) has been scientifically supported to improve health care outcomes and quality of life. However, health self-management research for adolescents with ASD has not been included when exploring health transition for other YSHCN. HSM is a multifaceted phenomenon especially when incorporated into the complexity of the family unit. A better understanding of the concepts, relationships, and processes occurring in the engagement of HSM for adolescents with ASD is needed to guide and support health care providers supporting this population. Therefore, the purpose of this cross-sectional descriptive correlational study aimed to provide critical first steps in examining the relationships between contextual and process variables and their influence on HSM behaviors in adolescents with ASD. Furthermore, the study compared child/parent perspective of the adolescent's HSM behavior that may relate to social facilitation of this

transition. The literature review presented in Chapter 2 provides a more comprehensive overview of HSM in adolescents with ASD and provides a basis for the design and methods described in Chapter 3.

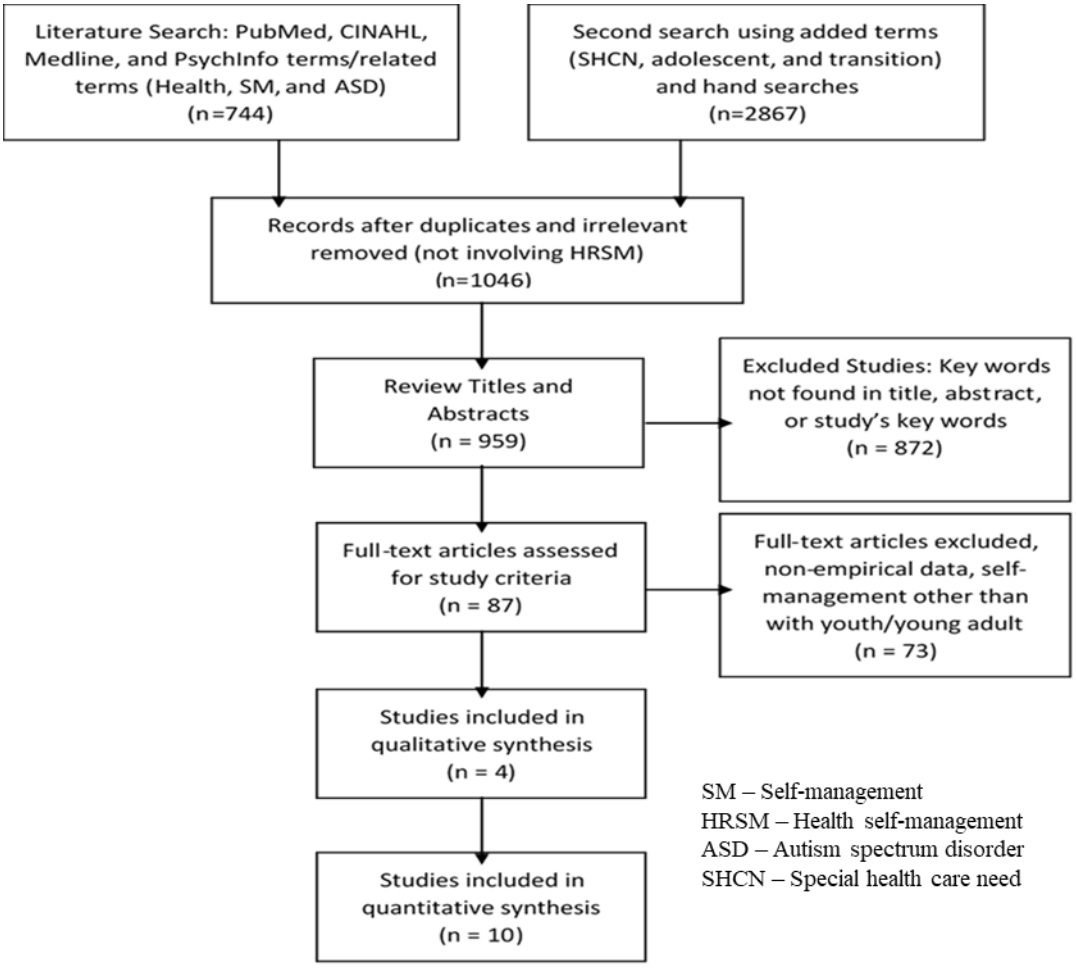
Chapter 2: Literature Review

This chapter reviews the literature relating to HSM in adolescents with ASD. When looking to provide the self-management support adolescents with ASD and their family need, it is helpful to consider what influences current HSM process and structure. Addressed in this chapter are the concepts and prepositions that emerged from the literature regarding HSM behavior. These identified concepts and relationships supported the foundation for the Adolescent Health Self-Management Model (see Chapter 1) used to guide this study. An integrative review of the literature and four existing theories (Individual and Family Self-Management Theory, Developmental Contextualism, Transition Theory, and Transtheoretical Model of Health Behavior Change) informed the development of the six domains and three theoretical statements supporting the Adolescent Health Self-Management Model.

REVIEW OF THE LITERATURE

A review of the literature on adolescent HSM was conducted to inform this study. To be included in the review, articles had to be published in peer-reviewed journals between 2007 and 2017 and address HSM or transition processes in adolescents or young adults with a chronic health condition. Articles were restricted to English language since translation resources were not available. An initial search in the databases PubMed, CINAHL, Medline, and PsychInfo for articles using the search terms health* self-management OR health* self-regulation OR health* intervention OR health management AND autism spectrum disorder OR ASD found few studies meeting inclusion criteria. Believing HSM to be in the literature relating to YSHCN transitioning from pediatric to adult healthcare providers, the search was expanded in these databases to include the additional key terms special health care needs AND adolescents OR youth OR young adult AND transition (see Figure 2).

Figure 2. Literature Review Search Methodology



After removing duplicate and irrelevant studies not relating to HSM or transitioning YSHCN, 14 studies (see Table 1) were found to meet inclusion criteria. While 10 of the studies addressed the health of other YSHCN, four specifically focused on transitioning adolescents with ASD, and only one explored health-related transition for adolescents with ASD. This one study exploring health transition in adolescents with ASD confirmed what the scarcity in the literature foretold, that adolescents with ASD experienced significant disparities in accessing health care transition services. The articles were reviewed for contributing self-management constructs and the resulting domain guided by the Individual and Family Self-Management Theory.

Table 1. Summary of Literature Review Articles

Health Care Self-Management for ASHCN			
Reference	**Objective(s)**	**Sample Description**	**Contributing SM Construct(s)**
1. Bauman et al. (2016) *Thrombosis Research*	Evaluate health care transition (HCT) abilities for adolescents/young adults (AYA) requiring indefinite warfarin therapy in a self-management (SM) program	• (N=19) AYA with chronic health condition • Autism spectrum disorder (ASD) Sample:(n=0)	Process Domain Proximal Outcome Domain Distal Outcome Domain
2. Fishman et al. (2010) Clinical Pediatrics	Evaluate success of adolescents with inflammatory bowel disease in developing SM skills prior to typical age of HCT	• (N=40) AYA with inflammatory bowel disease age 16 to 18 years/parent dyad • ASD Sample:(n=0)	**Adolescent Data** Process Domain Proximal Outcome Domain **Parent Data** Context Domain
3. Hodgetts et al. (2017) Disability and Rehabilitation	Examine perceptions and barriers to autonomous goal setting perceived by AYA with ASD, their parents, and interdisciplinary professionals	• (n=4) AYA with ASD aged 12 to 18 years • (n=7) Parents of children with ASD • (n=10) Interdisciplinary professionals • ASD Sample:(n=4)	**Adolescent Data** Process Domain **Parent/Professional Data** Context Domain Process Domain Distal Outcome Domain
4. Rehm et al. (2012) Advances in nursing science	Find meaning of adulthood for AYA/parent dyads planning for HCT and analyze impact of care on family roles and responsibilities	• (n=64) AYA with chronic health care condition and developmental disability • (n=74) AYA parents • (n=27) AYA health care providers • (n=46) AYA special education teachers • ASD Sample: unknown	Context Domain Distal Outcome Domain
5. Sawin et al. (2009) Rehab Nursing	Explore experience of SM in AYA women living with Spina Bifida and to better understand challenges faced	• (n=31) AYA women age 12 to 21 years with Spina Bifida • ASD Sample: (n=0)	Context Domain Process Domain Proximal Outcome Domain Distal Outcome Domain
6. Scal et al. (2009) Arthritis and rheumatism	Determine proportion of adolescents with arthritis who receive HCT services and compare to adolescents with diabetes and other youth with special health care needs	• Adolescents aged 12 to 17 years with arthritis (n = 1052), diabetes (n = 389), and other special health care needs (n = 17, 137) • ASD Sample: unknown	Context Domain Proximal Outcome Domain
7. Verchota & Sawin (2016) Nursing Research	Explore relationship of key SM context and process variables with proximal and distal outcomes in adolescents with type 1 diabetes mellitus	• (N=103) Adolescent girls with type 1diabetes between 12 to 17 years and parent dyad • ASD Sample: (n=0)	Context Domain Process Domain Proximal Outcome Domain Distal Outcome Domain
8.Warschausky et al. (2017) Pediatric Rehabilitation Psychology	Examine associations between generic and condition-specific health SM and levels of adaptive behavior in AYA with congenital neurodevelopmental conditions	• (n=43) AYA with cerebral palsy • (n=36) AYA with spina bifida/ myelomeningocele • ASD Sample: n = 0	Process Domain Context Domain Proximal Outcome Domain

Transition Management			
Reference	**Objectives**	**Sample Description**	**Contributing SM Constructs**
9. Cheak-Zamora et al. (2013) Pediatrics	Examine HCT services of adolescents with ASD using 2005-2006 National Survey of Children with Special Health Care Needs	• (N=18,198) Eligible youth with special health care needs age 12 to 17 years • ASD Sample: n=806	Context Domain Process Domain
10. Cole et al. (2015) Journal of Adolescent Health	Evaluate impact of HCT services on disease specific clinical and developmental outcome measures in adolescent inflammatory bowel disease	• (N=72) AYA with inflammatory bowel disease before age 16 from one gastroenterology clinic transitioning to adult services between January 2006 and January 2014 • ASD Sample: n = 0	Process Domain Proximal Outcome Domain Distal Outcome Domain
11. Dwyer-Matzky et al. (2017) Academic Pediatrics	Examine self-reported preparedness of hospitalized AYA for HCT services	• (N=139) AYA with special health care needs aged 15 to 25 years • ASD sample: unknown	Process Domain Proximal Outcome Domain
12. Griffin et al. (2014) The Journal of Special Education	Explore influences related to involvement in transition planning among AYA with ASD	• (N=320) high school students with ASD randomly selected from NLTS2 data set • ASD Sample: n = 320	Context Domain Process Domain
13. Hume et al. (2017) Autism	Determine level of transition-related skills of AYA with ASD from individual, parent, and teacher perspectives	• (n=534) AYA/parent dyad and teacher • ASD Sample: n=534	Context Domain Process Domain
14. Lindsay (2017) Disability and Health Journal	Understand spaces of well-being as AYA with physical disabilities experience HCT process	• (n=22) AYA with physical disability • (n=17) parents of AYA • (n=24) clinicians • ASD Sample: unknown	Context Domain Proximal Outcome Domain
Abbreviations: AYA – adolescents or young adults; HCT – health care transition; ASD – autism spectrum disorder; SM – self-management;			

ADOLESCENT HEALTH SELF-MANAGEMENT MODEL

Key factors of HSM and transition from the literature review were identified to guide development of the Adolescent Health Self-Management Model and their relationships to one another were proposed. The relationships among constructs presented in the model are consistent with existing evidence addressing health transition in YSHCN (Bauman, Kuhle, Bruce, Bolster, & Massicotte, 2016; Brown, et al., 2016; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011), although the specific research in youth with ASD is more limited. The concepts and relationships identified in the Adolescent Health Self-Management Model were developed using the strategies

of concept synthesis (grouping information about the phenomenon), statement synthesis (relationships among concepts), theory synthesis (combines relational statements into organized framework), and empirical evidence to develop theoretical statements used to guide research and practice (Walker & Avant, 2011). As Walker and Avant state (2011), "If concepts that are synthesized from practice or research form the building blocks of theory, then theoretical statements are the mortar that glues each block to its neighbor. In developing statements of relationships between concepts, the theory builder starts to bring clarity and direction to the understanding of phenomena of interest" (p. 119). The theoretical statements, key concepts, and supporting empirical evidence are outlined below.

THEORETICAL STATEMENTS OF THE MODEL

First Theoretical Statement

The first theoretical statement for the Adolescent Health Self-Management Model is that *health care providers engaging in family centered care, care coordination, and collaboration are key to improving adolescent with ASD readiness to engage in health self-management behaviors leading to improved health outcomes*. Although the healthcare provider domain is not addressed in this initial study, an understanding of the providers role in supporting HSM behavior from the literature provides a foundation for the missing aspects adolescents and parents face in this study. According to the American Academy of Pediatrics (2018), coordinated patient, family, and provider responsibilities facilitates the youth's ability to assume adult roles and activities. Since 2002, there has been a general consensus and widely accepted standard of quality practice among leading healthcare associations, families, youth, researchers, and policy makers that believe facilitating the planned transition of YSHCN into adulthood is of significant importance in maintaining health outcomes (Pediatrics, Physicians, & Medicine, 2002). Planned

transition includes increasing condition specific knowledge, building mastery of skills in self-management and self-advocacy, learning about appropriate models of care, and assigning expectations that the adolescent will ultimately assume responsibility for managing his/her health to the best of their ability (Brown, et al., 2016).

Based on the elements of the Individual and Family Self-Management Theory, individual and family risk and protective factors such as the complexity and stability of the adolescent's condition or treatment can challenge or enhance the individual or family's engagement in self-management behaviors (Ryan & Sawin, 2009). Findings from the 2016 National Survey of Children's Health revealed that youth having ASD had approximately 4 times higher odds of unmet health care needs when compared to children not having disabilities and 2 times higher odds of unmet health care needs when compared to children with other disabilities (Karpur, Lello, Frazier, Dixon, & Shih, 2018). Many of these unmet healthcare needs relate back to individual and family risk and protective factors such as access to quality health insurance, access to coordinated care, access to family-centered care, family-level stress, socioeconomic status, number and stability of co-occurring conditions (Farmer, et al., 2014). Thus, health care professionals trained and knowledgeable about ASD and the challenges these families face are better able to provide the consistency in care and guidance that benefit adolescents with autism and their family's needs during the transition to HSM. In addition, The Individual and Family Self-Management Theory also identifies social facilitation as the relationships that enhance an individual's ability to change. Thus, given the already discussed role health care providers and parents play within guided transition, providers influence the adolescent's engagement in HSM behavior indirectly through the care they provide for the adolescent's specific health condition(s) and directly through coordinated care and guidance of social facilitation during the transition

process. Therefore, children with ASD having access to planned, family-centered, and coordinated care have fewer unmet health care needs and better health outcomes (Carbone, Behl, Azor, & Murphy, 2010; Farmer, et al., 2014; Karpur, Lello, Frazier, Dixon, & Shih, 2018). This stability in health condition(s) and collaboration between all stakeholders provides the adolescent the ability to focus on gaining the skills and ability to self- manage their own health, hence increasing readiness (American Academy of Pediatrics, 2011; Brown, et al., 2016; White, et al., 2018). While missing from this study, the ***Health Care Provider Domain*** is believed to be a vital guiding source and support in HSM behavior.

Second Theoretical Statement

The second theoretical statement for the Adolescent Health Self-Management Model is that *individual and family risk and protective factors may challenge or hinder the adolescent's readiness to engage in self-management behaviors thereby impacting health autonomy and improved health outcomes.* Guided by contextual concepts proposed by Sawin and colleagues in the development of the Ecological Model of Secondary Conditions and Adaptations, the ***Contextual Domain*** of the Adolescent Health Self-Management Model identifies contextual factors that impact individual and family engagement in HSM behaviors as complexity of condition(s), physical and social environments, and individual and family characteristics (Sawin, Bellin, Roux, Buran, & Brei, 2009).

Complexity of Condition(s). This variable includes the characteristics of conditions and necessary treatment(s) for ASD and/or health disorders(s) or preventative/supportive measures needed to manage health stability that influence HSM behavior (e.g. complexity of health condition, complexity of ASD, stability of condition). As discussed in Chapter 1, adolescents with ASD are at high risk for a multitude of co-occurring physical, mental, and developmental

health conditions. Yet, there is an absence of evidenced based theoretical models, assessment strategies, and supportive interventions for care providers trying to implement HSM processes (Betz, et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). As a result, adolescents and their caregivers are struggling to independently manage the child's current and future health without appropriate guidance (Hodgetts, Richards, & Park, 2017; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). This health care concern is supported by the *Midcourse Review* of *Healthy People 2020* which indicates that the percentage of YSHCN (age 12 to 17 years) receiving health transition services has fallen behind target goals. The review suggests that over a five-year period (2005 to 2010) little improvement (only 2.9%) was seen from baseline values indicating transition services continue to be a barrier to health care (Sinclair, et al., 2018).

Studies also indicate that youth with autism are often limited in participation or absent from other transition planning services that directly impact their future (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Hodgetts, Richards, & Park, 2017; Hume, et al., 2017; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). Professional service providers cite the complexity of the adolescent's ASD symptoms (communication ability, restricted interests) and complexity in health condition (multiple health conditions, cognitive ability, affect disorders) as barriers that limit or deter the individual's participation in self-management planning (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Griffin, Taylor, Urbano, & Hodapp, 2014; Hodgetts, Richards, & Park, 2017; Hume, et al., 2017). Assumptions about the youth's abilities and the lack of evidenced based strategies supporting some deficits within the ASD population do serve as a barrier. Parents and health care professionals in one study identified limited time, few tools facilitating adolescent participation, and lack of professional training as the reason for excluding adolescents with ASD from the self-management process (Hodgetts, Richards, & Park, 2017). However,

parents in the study were able to offer some strategies and approaches to overcoming their child's communication and language barriers allowing the youth to participate. Many stakeholders (individuals with ASD, parents, teachers, and health care professionals) value the importance of self-management skills and abilities in adolescents with ASD engaging in adult transition (Griffin, Taylor, Urbano, & Hodapp, 2014; Hodgetts, Richards, & Park, 2017; Hume, et al., 2017). Yet, despite this unilateral support, involvement of adolescents with ASD in transition planning and processes remains low (Griffin, Taylor, Urbano, & Hodapp, 2014).

The few studies found for adolescents with ASD transitioning to adult services rarely address health but are focused more on academic and occupational transition. Only one study of health care transition service utilization focused on adolescents with ASD was found (Cheak-Zamora, Yang, Farmer, & Clark, 2013). Using the 2005-2006 National Survey of Children with Special Health Care Needs, Cheak-Zomora and colleagues (2013), suggest only 21% of youth with ASD (aged 12-17 years) had received transition services (e.g. Did pediatrician: discuss shift to adult provider, health care needs of adults, health insurance retention, youth taking responsibility for his/her health care needs?). Over twice as many YSHCN with needs other than ASD in the study reported receiving comparable forms of transition services (43%). Additionally, the study found that having multiple health conditions in addition to ASD decreased the odds of receiving health care transition services by 81%. Subsequently, Karpur *et al.* found in their study of health disparities in children with ASD, that nearly two-thirds of YSHCN and ASD in their sample had four or more health conditions (Karpur, Lello, Frazier, Dixon, & Shih, 2018).

Physical and Social Environment. Physical and social environmental factors are the adolescent and family's physical and social risk, or protective aspects related to HSM (e.g. health

care access, culture, and social capital). The literature indicates that access to quality health insurance and services and access to family-centered care are barriers to meeting health care needs for individuals with ASD and their family (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Karpur, Lello, Frazier, Dixon, & Shih, 2018). Numerous studies have examined social determinants of health in relation to unmet health care needs. However, do these aspects also play a role in influencing the adolescent's ability to self-manage? In a study comparing health care utilization among youth with ASD, youth with other disabilities, and without disabilities, Karpur (2018) reports youth with ASD were at greater risk for unmet healthcare needs relating to health disparities (socioeconomic, ethnic, and gender) when compared to children with other disabilities and children without disabilities (Karpur, Lello, Frazier, Dixon, & Shih, 2018).

Racial and ethnic differences among youth with ASD can lead to difficulties in accessing quality healthcare. A study comparing the 2005/2006 and 2009/2010 National Survey of Children with Special Health Care Needs found that Black and Latino parents experienced significant disparities in the area of quality health care that was family centered in both National survey reports when compared to White parents (Magaña, Parish, & Son, 2015). The study found that for both reports Black and Hispanic parents were less likely to report that the provider helped parents feel like a partner, provider spent enough time with child, and provider was sensitive to family's values and customs. Moreover, in a study by Zuckerman *et al.* examining parental beliefs about autism treatment and prognosis the researchers found that parents having higher levels of education and income were more likely to feel they had the power to improve their autistic child's condition with treatment (Zuckerman, Lindly, Sinche, & Nicolaidis, 2014).

When exploring health care needs of youth with ASD, Cheak-Zamora *et al.* found that demographic and family variables had little predictive value in transition planning for

adolescents with ASD. In their sample, having a developmental disability, multiple health conditions in addition to ASD, and satisfaction with healthcare services were strong predictors of health transition behaviors (Cheak-Zamora, Yang, Farmer, & Clark, 2013). In contrast, Karpur *et al.* looked at contextual factors identified as pre-disposing factors (age, gender, race/ethnicity, and neighborhood characteristics), need-based factors (condition complexity, co-occurring conditions), and enabling factors (access to quality health care, access to family centered care, financial stability, parent marital status, and life stability) as predictors of unmet health care needs for children with ASD. In Karpur's study logistic regression models improved 150% when all three aspects of contextual factors were included (Karpur, Lello, Frazier, Dixon, & Shih, 2018). Karpur's study agrees with previous research suggesting a strong relationship between family contextual characteristics and increased risk of unmet health care needs for the adolescent with ASD (Berg, Shiu, Feinstein, Msalll, & Acharya, 2018; Giuseppina & Warfield, 2012).

Since HSM behaviors have not been specifically studied for adolescents with ASD, it is difficult to determine if the unmet healthcare risk factors mentioned above also apply to unmet HSM behaviors in this population. However, commonalities can easily be seen with high-risk contextual factors relating to both unmet health care needs and unmet HSM behaviors and it stands to reason a relationship exists. Verchota & Sawin (2016) tested contextual factors (depressive symptoms, regimen complexity, age, gender, and parent perceived family life difficulty) guided by the Individual and Family Self-Management Theory for their influence on the short-term outcome (self-management behaviors) and long-term outcomes (lowered A1c levels and increased diabetes-specific quality of life scores) in adolescents with Type 1 diabetes mellitus. The researchers found that moderate associations existed between increased regimen complexity (contextual factor) and lower A1c levels (long-term outcome) and depressive

symptoms (contextual factor) resulting in negative association with both self-management behaviors (short-term outcome) and quality of life (long-term outcome).

Individual and Family Characteristics. Individual and/or family characteristics are those factors that support or diminish HSM behaviors. Adverse family characteristics that contribute to unmet health care needs in adolescents with ASD and their family include income hardship, parental divorce, family conflict, substance abuse, and mental illness (Berg, Shiu, Feinstein, Msalll, & Acharya, 2018; Reed-Knight, Blount, & Gilleland, 2014). The presence of functional limitations such as diminished executive functioning, depression, and the absence of family resilience are also associated with unmet health care needs and the family's ability to engage in HSM behavior (Cheak-Zamora, Yang, Farmer, & Clark, 2013; Karpur, Lello, Frazier, Dixon, & Shih, 2018).

Executive function in ASD. Early autism studies suggested that some behavioral and motor autism traits stemmed from dysfunction of the neural system of the prefrontal cortex resulting in executive function deficits (Damasio & Maurer, 1978). Since that time, the theory of executive dysfunction has been used in numerous studies to address some of the core features seen in individuals with ASD (Chen, et al., 2016; Craig, et al., 2016; McCabe, Roediger, McDaniel, Balota, & Hambrick, 2010; van den Bergh, Scheeren, Begeer, Koot, & Geurts, 2014).

According to the theory of executive dysfunction, there are four domains that may directly impact a youth with ASD ability to self-manage their health care condition: inhibition (resistance to interference and proactive interference); working memory (visual and verbal processes); cognitive flexibility (intentional shift in thought or action in response to change); and planning (thinking ahead). A study by van den Bergh *et al.* suggests that adolescents with ASD experience age related differences in each of the four executive function domains (van den

Bergh, Scheeren, Begeer, Koot, & Geurts, 2014). The study used the Behavioral Rating Inventory Executive Functions measure to capture the perspective of parents of children (age 6-18 years) with ASD regarding their child's executive functioning in the four relevant subscales (inhibit, working memory, shift, and plan/organize). The executive function subscales were examined for their relationship to the youth's age and condition severity. The researchers found in their sample that there was no relationship between executive function deficits and symptom severity in youth with ASD. Regarding executive function deficits and age, however, the study found that youths had less planning and inhibition problems with increasing age. The one exception to this finding was in the 12-14-year-old age group where slightly more planning deficits were seen when compared to 9-11-year-old age group. Problems with cognitive flexibility were also less apparent in the 15-18-year-old age group. Age was not a factor in working memory and shift scales.

Clinical cutoffs for executive function problems in the sample were observed in 20% (planning) to 51% (cognitive flexibility). Most executive function deficits appear to improve with age in adolescents with ASD. A study examining executive function deficits and age in youth with ASD compared to typically developing age and gender matched peers (age 8-18 years) found that while adolescents with ASD continued to exhibit deficits in working memory despite their age when compared to typically developing peers, planning and cognitive flexibility differences between groups is only seen in the younger age groups (age 8-12 years) (Chen, et al., 2016).

These studies suggest the importance of measuring executive function for its possible correlation to self-management for adolescent with ASD, similar as with adolescents with other special health care needs (Reed-Knight, Blount, & Gilleland, 2014).

Depression in ASD. Depression is a significant concern for YSHCN undergoing transition. Having both a chronic physical illness and depressive symptoms result in poorer health care outcomes for adolescents despite increased health care utilization (Ferro, Gorter, & Boyle, 2015; Verchota & Sawin, 2016). This may be due to physical health problems generally taking priority when in the healthcare setting while mental health conditions may be overlooked or unaddressed. However, unmet mental health issues in the population are likely also related to psychosocial and environmental stressors threatening the individual's homeostasis. The allostatic load model represents the wear and tear on the body experienced from repeated stressful insults (Juster, McEwen, & Lupien, 2010). Repeated allostatic experiences result in the body reaching a threshold impacting the individuals mental or physical wellbeing. Having both a physical health condition and depressive symptoms among YSHCN have been associated with poor functioning, lower quality of life, and increased mortality rates (Ferro, Gorter, & Boyle, 2015).

How depression impacts an adolescent's ability to self-manage their health care condition is unknown since few studies have focused on adolescents having both conditions. A review of the literature for youth (aged 10-19 years) beginning in the year 2000 resulted in 129 articles addressing both psychiatric conditions and chronic health conditions (Brady, Deighton, & Stansfeld, 2017). Of these, 99 studies focused on a specific health care condition (69 of the 99 articles focused on asthma or diabetes). The reviews final sample included only 5 studies after adjusting for unmet content validity and inter-rater reliability requirements of the *Newcastle-Ottawa Quality Assessment Scale for Cohort Studies* criteria. This strongly limited the study's findings in an already scarce field of research. However, the review suggests a strong relationship between the special health care need (asthma and diabetes) and psychiatric condition (depression and anxiety) (Brady, Deighton, & Stansfeld, 2017). Considering youth with ASD

(aged 10-17 years) are 4 times more likely to have a depression diagnosis then their typically developing peers, matched for age and gender, it is of substantial concern to know how depressive symptoms may impact their HSM behaviors (Autism Speaks, 2017; Cummings, et al., 2016).

Protective factors and resilience in ASD. Protective factors for individuals with ASD do not exist as opposites to or in absence of risk factors. Protective factors for this population are the variables that diminish the impact of risk factors relating to a poor or severe prognosis and/or decrease the negative reaction to it (Szatmari, 2018). In other words, protective factors promote resilience in individuals with ASD and their family members (Bekhet, Johnson, & Zauszniewski, 2012; Szatmari, 2018). Resilience theory defines resilience as an individual's ability to balance risk and protective factors when facing adversity (Luthar, Cicchetti, & Becker, 2000).

Resilience in family members, especially relating to stress in parents of youth with ASD has been well established in recent years (Bekhet, Johnson, & Zauszniewski, 2012; Bonis & Sawin, 2016) and has resulted in the identification of variables indicating resilience in family members that include maturity of the child, social supports, time since diagnosis, cognitive appraisal. locus of control, and spirituality (Bekhet, Johnson, & Zauszniewski, 2012). These factors may relate to time and adaptability as a parent adjusts to their child being diagnosed with ASD. To date, no studies have specifically focused on resilience in the individual with ASD despite its known existence. For instance, in a large group of adolescents with ASD (n=320) examining involvement in transition planning, Griffin *et al.* (2014) found that active participation for students was predicted by increased opportunity to practice these skills. Interventions targeting school and home contextual factors during childhood have positive long-term effects on the lives of youth with ASD. In a longitudinal study, Woodman *et al.*(2016) followed a group of

individuals with ASD and their family for 10 years, beginning when the child was 10 years old or above examining contextual factors for school (inclusion in school) and home (maternal positivity) as predictors for three functioning outcomes: autism symptoms, maladaptive behaviors, and daily living skills (Woodman, Smith, Greenberg, & Mailick, 2016).

Using hierarchical multiple regression and controlling for natural maturity over time, the three outcome variables showed consistent improvement over the course of the study at six different time points. Both family and educational context factors were found to be significant predictors of positive influence on outcome measures in the study (Woodman, Smith, Greenberg, & Mailick, 2016). Moreover, similar longitudinal studies following children with ASD into adulthood are finding 10% to 15% of the sample experience a good adult outcome (Henninger & Taylor, 2013). This is in contrast to earlier studies that unanimously found negative contextual outcomes and poor quality of life for adults with ASD (Szatmari, 2018). What current studies suggest is a "better than expected outcome", which aligns with the works of Ann Masten, *Ordinary Magic: Resilience Processes in Development* (2001), in the development of resilience in child development research.

While autism is a spectrum disorder with a wide range of deficits and needs requiring person centered care, studies able to focus on factors designed to build resiliency in individuals with autism (e.g. rote memory, honesty) and family and environmental variables (e.g. positive parenting, school inclusion) may allow for a shift away from traditional studies in this population focused on modifying risk factors. Instead, studies can examine the strengthening impact of protective factors common to normal human development much like studies of youth with other special health care needs. This is an important step for individuals with ASD and their families that continue to struggle with poor outcomes and access to needed services.

Process Domain. The factors of the ***Process Domain*** in the Adolescent Health Self-Management Model are potentially modifiable variables contributing to knowledge, beliefs, skills, and abilities of both parents and their adolescent children as they engage in HSM behavior. A key aspect of this domain is the social facilitation between parent and adolescent that is necessary for the youth to safely transition into increased responsibility (Reed-Knight, Blount, & Gilleland, 2014; Ryan & Sawin, 2009). These variables are consistent with recommendations made by the Institute of Medicine report on Health and Behavior and the Integrated Theory of Health Behavior Change (Lorig, 2003; Pellmar, Brandt, & Baird, 2002; Ryan & Sawin, 2009; Ryan P. , 2009). In accordance with these theories, HSM readiness among adolescents with ASD is increased when they possess health knowledge, positive health beliefs supporting their HSM behavior (e.g. self-efficacy, aligned goals and outcome expectancy), and self-regulation skills and abilities to change health behaviors (e.g. self-determination, self-monitoring, goal setting, decision making). These factors guide health behavior and increase engagement in HSM behavior.

Knowledge and Beliefs. Knowledge and beliefs refer to the general and condition specific information and perceived purpose in managing one's health (Bodenheimer, Lorig, Holman, & Grumback, 2002; Lorig, 2003; Lorig & Holman, 2003). For individuals living with a chronic health care need there are tasks and skills necessary to successfully managing one's health condition and developing an understanding of that condition requiring a foundation of knowledge and education (Schulman-Green, et al., 2012). Though knowledge alone does not encompass self-management, living with a health condition requires psychological and emotional adjustment in integrating the health care condition into one's life (Bodenheimer, Lorig, Holman, & Grumback, 2002; Schulman-Green, et al., 2012). It is believed that the

understanding of one's health care condition along with the knowledge and purpose behind caring for that condition will build confidence and motivation to engage in self-management behaviors (Ryan & Sawin, 2009).

Self-efficacy is the confidence one has in their ability to achieve a specific behavior (Bandura, 1997). In a study by Fishman *et al.* (2010) researchers explored transition readiness using patient specific condition knowledge and self-efficacy in adolescents with inflammatory bowel disease (age 16-18 years) relating to the adolescent's engagement in self-management behaviors (Fishman, Barendse, Hait, Burdick, & Arnold, 2010). The study suggests that without the necessary knowledge and confidence regarding their health condition, adolescents remain highly dependent on their parents for maintaining their health condition (scheduling appointment (85%), requesting medication refills (75%), and contacting provider between visits (74%).

When using self-efficacy as a measure for adolescent HSM behaviors, self-efficacy should be measured via multiple stakeholder perspective as adolescents often rate their self-efficacy higher than parents. In a study evaluating general self-efficacy in adolescents with special health care needs in association with quality of life, adolescent (perceived) and parent (perceived) self-efficacy scores for the adolescent were compared using paired *t*-tests. Adolescents' perceived self-efficacy was a predictor in all quality of life domains, while parents' perspective of child's self-efficacy predicted only the adolescents' social quality of life (Cramm, Strating, Roebroech, & Nieboer, 2013). Parents' perspective may provide added information that youth themselves may not directly identify but should not be the only perspective used in determining the individuals physical and psychological well-being. Unfortunately, it is often only parents' perspectives solicited in many studies of youth with special health care needs (Tesfaye, et al., 2019).

There are different aspects of self-efficacy to consider that play a role in the adolescents' increased engagement in self-management that directly relate to adolescents with ASD in current research. According to Bandura, perceived self-efficacy plays a vital role in self-management due to its influence on self-regulation processes via cognition, motivation, and affective factors. Beliefs of personal efficacy influence what self-regulative standards are adopted by people, their positive or negative attitudes, their motivation, perseverance, resilience, and decision making (Bandura, 1997). Comprehensively, however, Bandura believed that self-efficacy beliefs are developed and strengthened through opportunity to master experiences, social modeling, and social influences (Bandura, Caprara, Barbaranelli, Gerbino, & Patorelli, 2003). But how do levels of self-efficacy impact youth with special health care needs learning during transition? In looking at transition readiness, Johnson *et al.* (2015) examined self-efficacy in relation to learning method preference of YSHCN (age 6 – 16 years). The study found that youth favoring health care providers over other sources of information (parents, internet, printed materials, etc.) scored highest on self-efficacy scores and transition readiness scores (Johnson, et al., 2015).

These findings suggest increased independence and personal autonomy are observed in transitioning YSHCN as their self-efficacy increases. Other studies have explored self-efficacy in relation to engagement of self-management behaviors impact on proximal and distal health outcomes. Verchota & Sawin (2016) measured self-efficacy of adolescents with diabetes and the ability to communicate with their provider relating to self-management behaviors and hemoglobin A1c levels. In the Verchota study, self-efficacy, depressive symptoms, and self-management behaviors explained 52% of the variance in the quality-of-life measure. In yet another study, feelings of increased self-efficaciousness such as perceived independence in hospital visits and consultations were most positively associated with transition readiness when

compared to other contextual and process variables (socio-demographic data, complexity of health care condition, ability to self-manage) in adolescents with special health care needs (van Staa, van der Stege, Jedeloo, Moll, & Hilberink, 2011). These studies indicate that the value of self-efficacy as a process factor as adolescents gain more responsibility in HSM behavior by having both direct and indirect impact on engagement in HSM.

Skills and Abilities. There are many skills and abilities people can possess and engage in that assist in health behavior change. The self-regulation skills and abilities that increase HSM readiness are self-monitoring, goal setting, reflective thinking, self-evaluation, management of responses, self-determination, and decision making/planning (Ryan & Sawin, 2009). For instance, Scal and colleagues analyzed 2005-2006 National Survey of Children with Special Health Care Needs data about supported health care transition for youth with arthritis, youth with diabetes, and youth with other special health care needs (age 12-17 years) (Scal, Horvath, & Garwick, 2009). This study found that while transitioning youth with arthritis are being encouraged to assume self-care responsibilities (74.8%), they are not provided the skills necessary to manage the changing needs for adults (52.1%), acquiring health insurance (22.5%) and guidance needed to transfer care to adult provider (19.0%) necessary for sustained transition to adulthood. The absent skills and abilities were similar for youth with other special health care needs, but behind youth with diabetes in the study. Young people's participation in decision making and inclusion in processes impacting their lives is associated with empowerment by increasing self-efficacy, self-esteem, autonomy, and belonging to community (Tesfaye, et al., 2019).

Self-determination theory is a well-established, empirically based theory of human motivation, development, and wellness that is necessary for self-regulation, life goals and

aspirations, creative problem solving, and self-management, among many other growth and development aspects (Deci & Ryan, 2008). Self-determination theory does not evaluate the amount of a person's motivation, but instead looks at the type of motivation a person exhibits as a predictor of performance, relational, and well-being outcomes. Autonomous motivation is the intrinsic and valued extrinsic motivation aspects that lead the person to self-endorsed action. External regulation, such as actions endorsed by reward, punishment, approval, avoidance of shame, or ego are controlled motivation, while amotivation refers to when people feel pressure to think or behave in a particular way (Deci & Ryan, 2008).

Autonomous motivation was evaluated in adolescents with ASD, their parents, and interdisciplinary professionals in focus groups answering open-ended questions in association with setting goals for future planning (Hodgetts, Richards, & Park, 2017). The study, which overwhelmingly relied on parental perspective, found that adolescents with ASD rarely were active participants in autonomous goal setting leading to amotivation as parents and professionals determined goals for the adolescent. Parents and professionals cited general (cognitive deficits), specific condition (communication, restricted interest), and systematic (time, caseload, funding) issues as barriers to adolescent's involvement in autonomous goal setting.

However, according to Deci and Ryan (2008), competence, relatedness, and autonomy are basic and universal needs and that by thwarting autonomous orientations for controlled orientations the results lead to limited satisfaction in competence and relatedness needs being met. Additionally, research has consistently shown that it is the autonomy orientation that is positively related to psychological health and successful behavioral outcomes (Deci & Ryan, 2008). Parents in the study acknowledged that there were "types" of goals they would set for their child, which they described as "good to", "good for", and "filler goals" and these goals

carried varied interest for their child. Thereby, results suggest alignment with the self-determination theory that by showing limited satisfaction in meeting some of their child's needs these parents will continue to fall short of providing autonomy. Self-determination has been well established as important for adolescents with special health care needs preparedness for health transition to adulthood. For instance, in a study by Dwyer-Matzky *et al.* (2017) higher autonomous motivation and perceived competence related to increased knowledge and a more positive attitude toward transition planning that lead to more health care transition preparedness (Dwyer-Matzky, Blatt, Asselin, & Wood, 2017).

Social Facilitation. Defined as the social influence, support, and negotiated collaboration taking place between the parent and adolescent, social facilitation factors include the emotional, instrumental, and/or informational influences that help the individual engage in HSM behavior (Ryan & Sawin, 2009). For instance, social facilitation includes what the parent is doing to support and prepare their child to manage their own health to the best of their child's ability and what the adolescent is doing to learn to engage in managing their own health. Providers also play a key role in guiding this facilitation between adolescents and parents. As social facilitation increases, HSM readiness increases. The Individual and Family Self-Management Theory describes social influence as a conversation exchange or dialogue where persons in a perceived authority position and in possession of specific knowledge and expertise guide and support individuals and families in directed health behaviors (Ryan & Sawin, 2009). As previously discussed, a shortage of knowledgeable, trained providers serves as a barrier in consistent, quality health care for individuals with autism. However, knowledgeable sources may include family, friends, members of community groups, or printed and/or electronic medium. The increase in autism awareness in the last decade has led to supported research and evidenced

based programs that positively influence the lives of individuals with ASD and their families (Autism Speaks, 2017; National Autism Center: A center of May Institute, 2015). While there are supportive programs now available for adults with ASD (Nicolaidis & Kripke, 2014), social influence in the area of HSM for adolescents and their family is scarce, if not entirely absent (Bonis & Sawin, 2016).

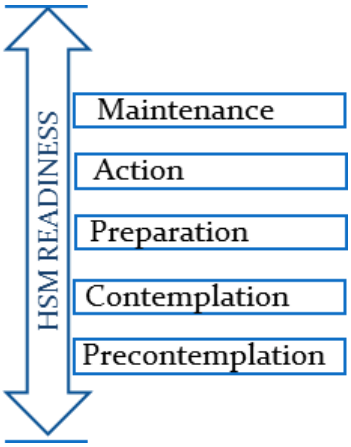
Social supports as described by the Individual and Family Self-Management Theory refers to the emotional, instrumental, or informational support provided to the individual or family in support of engaging in health behaviors (Ryan & Sawin, 2009). For typically developing adolescents, this stage of child development may take place naturally over time as youth mature and seek more responsibility and independence from their parents. However, for YSHCN, this important transition of responsibility is often given too early, delayed, unsupported, or absent (Reed-Knight, Blount, & Gilleland, 2014). Individual and family factors associated with failed allocation of self-management responsibilities during social facilitation include restrictive parenting, misaligned priorities, parental fear of declining health outcome, cultural barriers, family conflict, and adolescent readiness (Nazareth, et al., 2018; Reed-Knight, Blount, & Gilleland, 2014; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012; Sawin, Bellin, Roux, Buran, & Brei, 2009). It is assumed that these same factors are barriers for adolescents with ASD and their parents during social facilitation. However, health social facilitation between adolescent and parent has not been studied in this population. Never the less, studies have suggested these same barriers in transition for adolescents with ASD occur during transition to adulthood for aspects other than for health such as academic and occupation transition (Griffin, Taylor, Urbano, & Hodapp, 2014; Hume, Loftin, & Lantz, 2009).

Cultural beliefs of the parent may also play an important role in the adolescent acquiring independence in HSM. In an ethnography study of youth with both a chronic physical health condition and a developmental disability, their parents, health care providers, and special education teachers on the meaning of transition to adulthood, it was suggested that some families (most often African American and Asian participants) had a clear expectation of the youth's continued interdependence and cohabitation as both a normal and desirable outcome (Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). However, while being sensitive to individual cultural beliefs, the adolescents' normal growth and development in the area of personal autonomy, competence, and relatedness should strongly be considered for they predict psychological well-being in all cultures (Deci & Ryan, 2008).

HSM Readiness. The transtheoretical model theorizes that health behavior change involves progressing through six stages of change: precontemplation, contemplation, preparation, action, and maintenance (Norcross, Krebs, & Prochaska, 2011; Prochaska & Velicer, 1997). The stages of change, or readiness to change, have been used in countless health behavior studies measuring readiness, motivation, decision making, adherence to treatment, and self-efficacy in attempts to better understand how to support individuals wanting to make lifestyle change. For adolescent HSM, these stages of readiness are briefly discussed in Chapter 1; however, to better understand how these stages represent the process of HSM readiness they are examined here in greater detail (see figure 3).

For each stage of readiness within HSM, there is an internal process that the adolescent with ASD will experience that leads to one of three conclusions: a side-ways step (stay in current stage), a regressive step (regress to an earlier stage), or a progressive step (move forward to higher stage) (Prochaska & Velicer, 1997). How this internal process, or decisional balance,

Figure 3. HSM Readiness

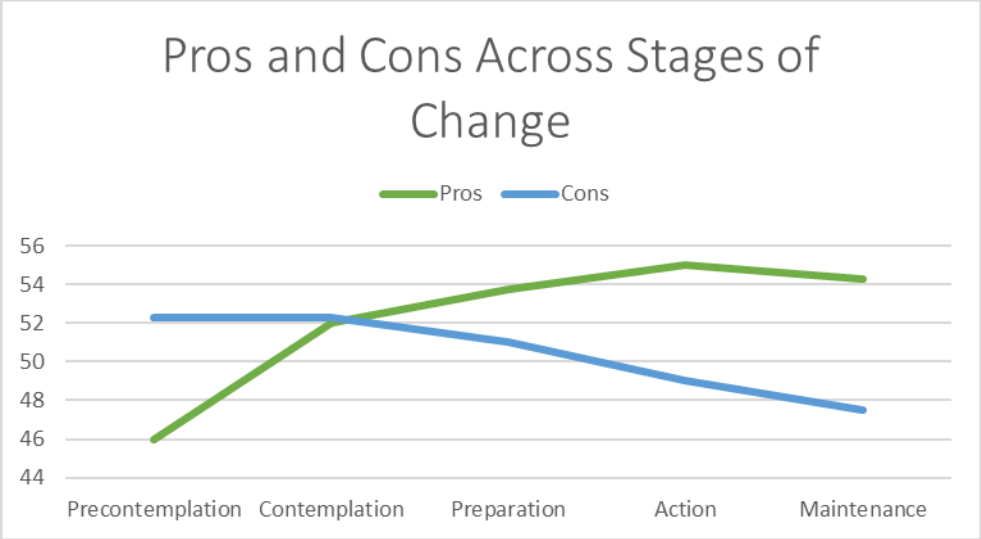


is determined is based on the individuals cognitive and motivational "weighing" of the pros and cons involved in engaging in self-management behavior. Contextual and process factors may influence the decisional balance as well. The pattern for decisional balance across stages of readiness is very well established in health behavior change studies (Prochaska J. O., 2008). Taken from a meta-analysis of 50 diverse health-related studies by Hall and Rossi (2004), Prochaska analyzed the structure of pros and cons across the stages of readiness (see figure 4).

The idea behind decisional balance in HSM readiness is to target the adolescents need for support and intervention based on the stage of readiness they are currently in. For instance, an adolescent with ASD in the precontemplation stage of readiness, exhibits significantly more cons than pros in engaging in HSM. This may be due to the adolescents' lack of awareness that they would benefit from this health behavior change and therefore do not possess the necessary knowledge, beliefs, skills, abilities, or social facilitation necessary to change the decisional balance. Therefore, the adolescent will take a side-ways step and stay where they are in their readiness to engage in HSM behavior. However, if provided support and guidance in these process variables, the adolescent is empowered and gains the confidence to maybe try HSM behaviors. Thereby the pattern of the decisional balance is changed when perceived pros in

engaging in HSM behavior is increased and cons decreased, which may lead to progression to the contemplation stage of readiness.

Figure 4. Decisional Balance (recreated from (Prochaska J. O., 2008).



Engagement in the process domain and increased HSM readiness as described in the Adolescent Health Self-Management Model are believed to result in positive change on the variables found in the ***Proximal Outcome Domain***. The variables of the proximal outcome domain include the short-term actions such as engagement in HSM behavior and appropriate health care use that support distal outcomes (Bodenheimer, 2005; Ryan & Sawin, 2009). Proximal outcomes can be assessed while the adolescent is making the transition to adulthood and are believed to result in progress on the variables of the ***Distal Outcome Domain***. Distal outcomes are long-term effects that result from proximal outcomes. They include ownership of health status, personal autonomy, quality of life, improved health care outcomes and efficient direct/indirect health costs.

Third Theoretical Statement

The third theoretical statement for the Adolescent Health Self-Management Model is that the adolescent transition to HSM does not occur in isolation and that *the types, patterns, and*

properties of co-occurring transitions for both the adolescent and parent during the HSM transition process may impact the adolescents' engagement in HSM behavior and health autonomy. The characteristics of transition are not specifically addressed in this study; however, a foundational understanding of the transition process used in this study is warranted. Therefore, a brief discussion is included in this literature review. Guided by Meleis's theory, the ***Transition Domain*** includes developmental transitions such as adolescence to adulthood and health/illness transitions that require taking ownership and increased responsibility for one's health condition. These transitions are described by Meleis (2000) as vulnerable periods of time when individuals are at increased risk for problematic recovery, damaging illness, and/or delayed or unhealthy coping. Therefore, the adolescent and/or parent may need additional support or intervention during the transition process.

Characteristics identified in this domain are adolescent and parent transition(s) experienced while undergoing HSM transitions that impact the individual's ability to engage in self-management behaviors. Understanding the transition characteristics provides anticipatory preparation for the transition which facilitates the experience, whereas lack of preparation is an inhibitor. These attributes include types of transition (developmental, situational, health/illness, organizational), patterns of transition (single, multiple, sequential, simultaneous, related), and properties of transition (awareness, engagement, critical points/events) that may require additional support and/or intervention to facilitate preparation. For instance, adolescents undergoing HSM transition are also experiencing a developmental transition into adulthood and may struggle with competing responsibilities. Simultaneously, parents are also transitioning into their new consultant role (Meleis, Sawer, Im, Messias, & Schumacher, 2000). Understanding that all three transitions carry a different meaning to the individual experiencing the transition will

facilitate anticipatory preparation and collaboration. Identifying the type, pattern, and property of the transition taking place and in whom is vital to engagement of HSM to fully understand how all stakeholders are impacted.

Time in the Adolescent Health Self-Management Model

Time is the last key concept of the model. Throughout the transition process outlined here, time is an important construct. A key dimension of time is the developmental maturation of the adolescent as they move through this process. This developmental process may not always follow a predictable linear increase corresponding to chronological changes in time. An adolescent may spend more time in some phases or aspects of the process than others. Crucial factors in the contextual, transition, and health provider domains, including the adolescents' life history, can accelerate or decelerate the transition process (Lerner R. M., 1992; Lerner, Sparks, & McCubbin, 1999).

GAPS IN THE LITERATURE

This review of the literature truly reflects the early state of research focused on adolescent HSM and ASD. Contextual variables known to exist and impact YSHCN and their family's ability to self-manage either are limited in ASD or have not been studied to date. Given the ubiquity of risk factors and protective factors seen across all YSHCN leading to unmet health care needs it is logical to assume that these variables also relate to an autistic adolescent's ability to self-manage their health care condition. There is sufficient research available in this area to support this assumption. However, given the state of ASD specific research we cannot assume that all these same risk and protective factors apply to the same extent and patterns for adolescents with ASD. As previously discussed, while there are many commonalities seen in general health care conditions for all YSHCN, there are condition specific aspects of ASD that

set adolescents with this disorder apart (Warchausky, Kaufman, Schutt, Evitts, & Hurvitz, 2017). The limited amount of condition specific health research for adolescents with ASD represents a noticeable gap in the literature. This gap in the literature has resulted from the adolescent with ASD being lost in other YSHCN data, especially when using national survey data that does not always differentiate between diagnoses in YSHCN.

Variables in the process domain include knowledge and beliefs, self-regulation skills and abilities, social facilitation, and HSM readiness. Although we have limited information about these variables for adolescents with ASD engaging in self-management behaviors it is assumed that not providing opportunities to gain the same skills and abilities afforded other YSHCN will impede their HSM (Griffin, Taylor, Urbano, & Hodapp, 2014). Additionally, social facilitation occurring between adolescents with ASD and their parent in developing the adolescent's knowledge, skills, and abilities for HSM has not been assessed in the literature, and it is unknown if it is occurring at all. Lastly, capturing both independence in HSM behaviors and readiness to engage in HSM behaviors may provide a comprehensive assessment of the likelihood for sustained HSM behavior not assessed in the current literature.

CHAPTER SUMMARY

Unmet health care needs in the ASD population have forced individuals and families to carry a heavy burden in maintaining health stability and can result in poor long-term health outcomes and poor quality of life. Risk and protective factors of contextual variables such as complexity of the child's ASD and family resilience add to the intricacy of the HSM phenomenon by negatively or positively influencing the family's ability to engage in HSM, thereby possibly increasing the risk for unmet health needs (Berg, Shiu, Feinstein, Msalll, & Acharya, 2018; Karpur, Lello, Frazier, Dixon, & Shih, 2018). Additionally, as adolescents with

ASD mature and gain independence from their parents, the transition of health care responsibility viewed as normal growth and development for typically developing peers, may not occur. The lack of empirical data in this area for adolescents with ASD and their families only complicates the HSM phenomenon further. However, as suggested by Cheak-Zamora et al. (2013), adolescents with ASD are prepared to self-manage their own health less than youth with other special health care needs.

In the following chapter, the methods of this descriptive correlational study are described.

Chapter 3: Methods

This chapter describes the research methodology used to explore variables contributing to the development of HSM behaviors in adolescents with ASD. Presented is a description of the study research design, sample and selection criteria, instrumentation and related psychometric properties, data collection and processes, analysis of data procedures, and processes to ensure the protection of human subjects.

RESEARCH DESIGN

Quantitative research studies provide an objective approach for testing theories by examining the relationship between variables (Creswell, 2014). In this dissertation study, a postpositivist worldview is followed where data and evidence are used to shape knowledge. Creswell states that postpositivists believe causes probably determine effects or outcomes. (Creswell, 2014, p. 7). Therefore, the goal of a postpositivist is to carefully observe and measure the causes that influence outcomes in the objective reality. Furthermore, it is believed that there are theories that govern the objective reality. Research conducted by the postpositivist begins with a theory, collects data to support or refute the theory, makes decisions or revisions based on the data results, and then conducts more tests. Creswell goes on to say that nonexperimental quantitative designs such as survey research within a study sample population provides a numeric descriptive of trends, attitudes, or opinions of that population (Creswell, 2014). Therefore, a cross-sectional descriptive correlational survey design was used to explore variables relating to adolescent HSM behaviors guided by the Adolescent Health Self-Management Model. Content analysis was utilized to examine parent and adolescent fill-in answers to items about social facilitation of adolescent HSM when participants felt drop down selection options did not fully capture their experience.

PRELIMINARY WORK

A qualitative descriptive study was conducted by the PI to inform this dissertation study. In that study, parents of children with ASD were interviewed for their perspective of caring for their child's health care needs. Findings (N=6) from the study suggest that parents of transition age children received little, if any, exposure to formal HSM as recommended by the American Academy of Pediatrics. Moreover, parents often felt isolated and overwhelmed in managing their child's health. Subsequently, most parents in the study exhibited symptoms of chronic sorrow, which may hamper the social facilitation process (Rock & Becker, 2020). Therefore, exploring the status of HSM behavior and belief of parents and adolescents may provide valuable first steps in increasing HSM in adolescents with ASD.

SAMPLE AND SELECTION CRITERIA

In this dissertation study, initially adolescents aged 14 to 22 years and their parent or family caregiver were asked to participate. Participant eligibility criteria for the adolescent included diagnosis of ASD, enrollment in 6th grade level or above, ability to read and write English, and able to give assent/consent, and their parent or family caregiver also consenting to be in the study. The transition algorithm established by the American Academy of Pediatrics recognizes all adolescents as developmentally ready for introduction of HSM transition beginning at age 12 (American Academy of Pediatrics, 2011). Given that health transition is often delayed in YSHCN, reaching a 6th grade level or higher and requiring adolescents to be 14 years or older should assure age-related developmental readiness (Fortuna, Halterman, Pulcino, & Robbins, 2012; Oswald, et al., 2013). However, once recruitment for the dissertation study began, multiple contacts from perspective parent participants were received stating that their child met eligibility criteria outside the minimum required age 14 years. Therefore, after careful

consideration and discussion with the Committee Chair, an IRB addendum was sought to lower the adolescent participant age to 12 years to better align with American Academy of Pediatric recommendations and better reflect the abilities and disabilities represented along the autism spectrum. Although the initial sample was proposed to come from Central Texas, parents in other parts of Texas became aware of the study and asked to participate. After consultation with the dissertation committee, an addendum was submitted to the IRB to broaden recruitment to the state of Texas. To accommodate possible requested distance support from the PI by participants, an option for video conferencing was also added to the addendum. Also, despite IRB approval for a waiver of documented signed informed consent, a request to add informed consent forms at the beginning of the Qualtrics survey was requested to further establish desired participation and understanding of participant rights. These addenda were approved on November 12, 2019 and January 17, 2020 and recruitment efforts indicated these changes (key supports were notified and IRB approved flyers redistributed).

Regarding age selection for participant eligibility, Healthy People 2020 recognizes adolescents (ages 10 to 17) and young adults (ages 18 to 25) as a time of rapid growth and development when individuals are particularly vulnerable and sensitive to environmental influences impacting their health (Office of Disease Prevention and Health Promotion, 2019). It is not uncommon for YSHCN to remain with pediatric healthcare specialists well after American Academy of Pediatric recommended transition to adult provider between the age 18 to 21 years. It stands to reason that this delay to an adult provider may also reflect a delay in self-management behaviors (American Academy of Pediatrics, 2011; Fortuna, Halterman, Pulcino, & Robbins, 2012). Additionally, the Individuals with Disabilities Education Act (IDEA) recognizes individuals with a disability and ensures free and appropriate public education up to age 22

years, meaning that individuals with disabilities aged 3 to 22 years can receive special education services within public schools and many still reside in the family home. Therefore, in this dissertation study adolescents and late adolescents are recognized as aged 12 to 22 years. Additionally, Locke and Mitchell (2016) found in their study of adolescents with and without ASD aged 12 to 18 years that participants having a 6th grade reading level, as determined by a parent and/or clinician familiar with the adolescent, were able to independently complete the 16-item, 11-point rating scale questionnaire to measure self-efficacy in their study (Locke & Mitchell, 2016). Adolescents in this dissertation study had an existing diagnosis of ASD at the time of recruitment, which was based on parent report. Parents taking part in the study also had to read and write in English. Both parents and adolescents also had to have access to a smart phone and/or internet services. Adolescents, parent or family caregivers unable to cognitively comprehend or complete the required survey packet even with the support of the PI (e.g., accessing survey packet because of connection issues or rephrasing questions of the survey packet to support participant understanding) were excluded from participation.

RECRUITMENT/ENROLLMENT

A convenience sample of adolescents with ASD/parent dyads were recruited from local agencies and organizations supporting individuals with ASD and their families living in Texas from October 2019 to December 2020. Prior to the COVID-19 pandemic shutting down the economy in March 2020, the local chapter of Autism Society of Texas, Texas Center for Disability Studies, HCC Life Skills and Transition Services, Easter Seals (Houston), Autism Speaks (Texas), and Texas Parent-to-Parent had posted study flyers to their social media listservs (Facebook, Yahoo, Meetup, and Face-to-Face). The PI also provided presentations to providers, individuals, and parents for the Autism Providers Network, Autism Society of Texas, Integral

Care, University of Texas Autism Consortium, and Dell Children's Hospital. Furthermore, the PI had attended several support groups and made contacts at Autism Society of Texas and Parent-to-Parent and planned to recruit directly via scheduled autism events over spring and summer 2020. Study flyers were shared with these contacts, which they were asked to share with parent of adolescents with autism. Unfortunately, when COVID-19 cases began to increase in Texas, many of these events were cancelled and recruitment efforts were limited to virtual only efforts yielding very little progress. Prior to March 2020, study participant dyads had completed 22 surveys. Since March 2020, only 18 dyads have completed the survey despite continued recruitment efforts.

POWER ANALYSIS

A power analysis for bivariate correlation was conducted in G-POWER to determine a sufficient sample size using an α=0.05, a power of 0.80, an effect size (r = 0.47) between self-management behaviors and communication measure, with two tails (Verchota & Sawin, 2016). This calculation resulted in a recommended sample size of 30. For the hierarchical regression analysis, calculations for effect size were based on previous research (Farmer, et al., 2014). In that study, a dependent variable of children's unmet needs for specialty care was predicted by two sets of predictors: child family and child health. The first block of child family predictors alone accounted for 4% of the variation of dependent variable, thus R^2=0.03. Including the second block of child health increased the proportion of variance explained to 0.33, thus R^2 for the whole regression model was 0.33. To calculate the effects size, the option from variance in the effect size drawer was used. In the input field variance explained by special effect was inserted R^2=0.33 – 0.3 = 0.30., and Residual variance we inserted as 1 – R^2= 1 – 0.33 = 0.67. Based on these numbers, a partial R^2=0.309 and an effect size f^2= 0.448 were calculated. Given

a = 0.05, power = 0.8, effect f^2= 0.448, and 5 predictors (3 predictor in first block and 2 additional predictors in second block), total sample size was recommended to be 26. Therefore, in this dissertation study 40 adolescent/parent dyads participated in the study met the desired sample size.

MEASURES AND INSTRUMENTATION

Measures

A combination of 11 study measures were utilized to capture contextual and process constructs as identified in the Adolescent Health Self-Management Model for this study (see Table 2). There are two separate sets of adolescent HSM measures to be considered: measures completed by the adolescent with ASD and measures completed by their parent/caregiver. One measure was completed by the adolescent only, five by parent/caregiver only, and six measures were completed by both adolescent and parent. All measures were designed to be completed by the adolescent and the parent independent of each other via individual survey links.

Table 2. Summary of Measures

Domain	Adolescent Construct	Measure	Item Number	Completed by
Contextual	Demographic Data – access to family centered care, SES, race, ethnicity, gender, age	Background Information Questionnaire	23 items	Parent
	Complexity of ASD	AQ-10 (Adolescent Version)	10 items	Parent
	Learning/cognitive ability	Barkley Deficits in Executive Functioning Scale – Children and Adolescents − Short Form	20 items	Parent
	Complexity of health condition	Children with Special Health Care Assessment	5 items (yes/no)	Parent
	Depressive symptoms	PROMIS Emotional Distress-Depression-Peds Short Form	14 items 11 items	Adolescent – Peds version Parent-parent version

		PROMIS-Depression-Parent/Guardian of Child Age 6-17-Short Form		
Process	Health Communication /Planning Health knowledge	Star$_x$ – Health Care Transition Readiness Questionnaire for youth with chronic health condition Star$_x$-P – Health Care Transition Readiness Questionnaire for parent of youth with chronic health condition (on child's readiness)	3 items: Provider communication 3 items: Planning 3 items: Health condition knowledge	Adolescent – adolescent version Parent – parent version
	Self-efficacy	General Self-Efficacy Scale	10 items	Adolescent – adolescent version Parent – parent version
	Self-determination	AIR Self-determination Scale	24 items	Adolescent – adolescent version Parent – parent version
	HSM Social Facilitation	Question with drop-down menu	2 items (drop-down options with optional short answer space) 1 item (drop-down options with optional short answer space)	Adolescent – What does your parent do to help you learn how to manage your health? What do you do on your own to take care of your health? Parent – What do you do to help your child learn how to self-manage their health?
	HSM perceived barriers	Question with drop-down menu	1 item (drop-down options with optional short answer space)	Parent – What are your barriers to teaching your child how to self-manage their health?
	Stages of Readiness to Self-Manage	Stages of Change (Short Form)	4 items (yes/no)	Adolescent
Proximal Outcome	HSM Behaviors	Star$_x$ – Health Care Transition Readiness Questionnaire for youth with chronic health condition Star$_x$-P – Health Care Transition Readiness Questionnaire for parent of youth with chronic health condition (on child's readiness)	9 items: Self-management Behaviors	Adolescent – adolescent version Parent – parent version
Completed By: Parent/Caregiver ☐ Adolescent ☐ Parent/Caregiver & Adolescent ☐				

Instrumentation

The instruments selected for this study were chosen to capture the complexity of adolescent and parent perspective known to accompany health transition. Except for the Stages of Change scale, most of the instruments have been tested in previous studies and found to be reliable, and valid when conducted in the target population or similar populations as indicated. The chosen instruments and their psychometrics are presented here and listed by measures completed by the adolescent and then measures completed by the adolescents' parent or caregiver.

Adolescent Measures. ***PROMIS Emotional Distress-Depression-Peds Short Form*** is a 14 item, self-report survey answered on 5-point Likert scale ranging from 1 (never) to 5 (almost always) that measures depressive symptoms in children and adolescent age 11 to 17 years. Well established measure. **Higher scores indicate more depressive symptoms (score range 14-70).** Demonstrated to have adequate reliability and validity when measuring depressive symptoms (negative mood, self-view, little pleasure) in adolescents with special health care needs (α=.95) (DeWalt, et al., 2015; Verchota & Sawin, 2016). This dissertation study α was .91. (Appendix A)

STAR$_x$ Transition Readiness Questionnaire − adolescent version is a total of 18-items via self-report questionnaire measuring 3-domains: health knowledge, health communication & planning, and health self-management behaviors. Answered on 5-point Likert scale with item scores ranging from 1 (never, very hard, or nothing) to 5 (always, very easy, a lot), and an additional selection of 0 (I do not take medicines right now), when applicable. For adolescents not taking medication, a value indicating the average item score was input for medication items when creating a total score on the health self-management behavior scale. Each item is scored individually and worth a maximum of 5 points. Health Knowledge subscale score ranges from 0-

15, Health Communication & Planning subscale score ranges from 0-30, and HSM Behaviors subscale ranges from 0-45. Subdomain scores can be combined to create a total score, ranging from 0 – 90. **Higher scores reflect greater health self-management knowledge (3 items), communication & planning skills (6 items), and engagement in self-management behaviors (9 items).** Reliability estimates reveal good internal consistency and temporal stability, with the alpha coefficient for the overall scale being .80 in youth with special health care needs (Ferris, et al., 2015). The $Star_x$ Questionnaire and its subscales reflect strong concurrent validity, predictive validity, and discriminant validity when compared with other transition readiness tools when used with three different clinical conditions (Cohen, et al., 2015; Nazareth, et al., 2018). In the dissertation study: Health Knowledge $\alpha = .69$, Health Communication/Planning $\alpha = .71$, and HSM Behavior $\alpha = .65$. (Appendix B)

General Self-Efficacy Scale is a 10 item, self-report survey used to measure one's confidence in their ability to influence outcomes. Responses are made on a 4-point Likert scale (1 = not true at all, 2= hardly true, 3 = moderately true, 4= exactly true) to items such as "I can always manage to solve difficult problems If I try hard enough." **Higher score indicates higher self-efficacy (score range 10-40).** Internal reliability Cronbach's alphas range from 0.76 to 0.90 in adolescents with special health care needs. Construct validity was established through positive correlation to emotion, optimism, work satisfaction, and negative coefficients for depression, stress, health complaints, burnout, and anxiety. Criterion validity was established through correlations to personal demographic variables (number of jobs, education level, military rank) (Schwarzer & Jerusalem, 1995; Cramm, Strating, Roebroech, & Nieboer, 2013). In the dissertation study α was .76. (Appendix C).

AIR Self-determination Scale – student version is a 24 item self-report survey answered on 5-point Likert scale ranging from 1 (never) to 5 (always). Based on self-determined learning theory, there are two domains: Capacity (ability and perception) and Opportunity (at school and at home). The AIR-S (student version) has questions in the Capacity subscale consisting of 12 items: "Things I Do" related to self-determination ability and "How I Feel" about performing self-determination behaviors. The Opportunity subscale consists of 12 questions about the participants perceptions of their opportunities to engage in self-determination behaviors at home and school. Both Capacity and Opportunity scores are calculated and combined for a total self-determination score of 24-120. However, due to the diverse age range of participants, some adolescents were not currently attending school. Therefore, a new variable was calculated for opportunity to represent self-determination opportunity at home only. The adjusted total self-determination score ranged from 18-90. **Higher scores indicate a higher level of self-determination either in capacity or opportunity or both.** Reliability of the short form AIR is supported in adolescents with ASD aged 13 to 21 years with and without IDD. There were Cronbach's alpha of .91 and .87 for subscales Capacity and Opportunity, respectively. Cronbach's alpha for total self-determination score was .93. Adequate item reliability and standard factor loadings also support reliability in adolescents with ASD population. Discriminant validity of AIR in adolescent ASD population was supported by factor correlation between capacity and opportunity less than .85 and significant likelihood-ratio test ($\Delta_x^2 = 314.68$, $\Delta df = 1$, $p < .001$). (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2017; Shogren, et al., 2008; White, Flanagan, & Nadig, 2018). In the dissertation study $\alpha = .88$. (Appendix D)

Stages of Change: Short Form is used in this study to assess the adolescent stage of readiness. It is a 4 item self-report survey answered categorically yes/no. The stages of change

algorithm consist of a brief series of self-report questions assessing health behavior change activities. **Higher perceived engagement in health behaviors is assumed to indicate a higher level of being prepared and willing to engage in health self-management.** The Stages of Change-short form has only been used to assess weight management readiness and is based on the 12-item short form of the University of Rhode Island Change Assessment (URICA). This questionnaire was adapted to reflect engagement of HSM behaviors instead of engagement in physical fitness behaviors in adults. The URICA has well established reliability studies using internal consistency measures. Content, criterion (predictive, concurrent, "postdictive"), and construct validity have been established in many different behavior change studies since 1983. This instrument has not been used in adolescents with ASD or special health care needs (Mander, et al., 2012; University of Rhode Island, 2019). (Appendix E)

Parent Measures. ***Background Information Questionnaire*** (Appendix F) designed by the PI contains basic sample demographic questions relating to the parents age, gender, level of education, SES, race, ethnicity, marital status, type of insurance, number of children in the household, and access to family-centered care. Demographic data relating to the adolescent includes age, gender, level of education, race, ethnicity, specific health condition status, age at ASD diagnosis, and years since ASD diagnosis.

AQ-10 (Adolescent Short Form) used to assess complexity of adolescents ASD symptomology. Questionnaire contains 10 items assessing autism symptomology in adolescents by asking related questions such as “If there is an interruption, s/he can switch back to what s/he was doing very quickly”. Answered on an adapted 4-point Likert scale, Definitely Agree, Slightly Agree, Slightly Disagree, Definitely Disagree. **Higher scores indicate greater complexity of ASD condition (score range 10-40).** Psychometric properties in a large-scale

study for referral to specialist assessment for ASD - a cut-point of 6 on the original scoring of AQ-10 adolescent, corresponded to sensitivity of 0.93, specificity of 0.95, and positive predictive value of 0.86. Internal consistency was >0.85 (Allison, Auyeung, & Baron-Cohen, 2012). In the dissertation study $\alpha = .77$. (Appendix G)

Children with Special Health Care Need Assessment (actual name: Children with Special Health Care Need Screener) used to assess complexity of adolescents' health condition. Assessment consists of 5 item, parent survey-based branching tool answered yes/no. Developed to identifying youth at high risk for special health care needs, it was specifically designed to reflect the federal Maternal and Child Health Bureau definition of children with special health care needs meaning being both at high risk for chronic health condition and in elevated need of services. The scale uses non-condition specific, consequence-based criteria to identify children with special health care needs. **More "yes" answers to assessment questions indicated higher complexity in physical, developmental (other than ASD), behavioral, and/or emotional health condition (score range 0-14).** It was validated as a population-based tool estimating prevalence of children with special health care needs and comparing needs and health care system performance across states and population subgroups in 2001, 2005–2006, and 2009–2010 National Survey of CSHCN (NS-CSHCN; n = 1,106,974); the 2003, 2007, and 2011–2012 National Survey of Children's Health (NSCH; n = 289,672); and the Medical Expenditure Panel Survey (MEPS) since the year 2000 (n = 113,729) (Bethell, et al., 2015; Bethell, et al., 2002; The Child and Adolescent Health Measurement Initiative, 2002). In the dissertation study $\alpha = .91$. (Appendix H)

Barkley Deficits in Executive Functioning Scale – Children and Adolescents − Short Form used to evaluate adolescents' executive function abilities. Questionnaire consists of 20

items assessing the frequency at which child exhibits behaviors in specific areas of executive functioning over the previous 6 months. Areas examined include self-management of time, self-restraint, organization/problem-solving, self-regulation of emotion, and motivation and was created and normed for parent report in evaluating their child (aged 6–17 years). Executive function deficits are measured using a 4-point Likert scale, ranging from never or rarely (1) to very often (4). **Higher scores indicate more severe executive functioning deficits exhibited by the adolescent (score range 20-80).** In a large nationwide normative sample containing adolescents with and without special health care needs, including ASD, evidence of high reliability was determined by internal consistency (Cronbach's alpha ranging from .95 to .97 scores across five scales) and high test–retest reliability (ranging from .73 to .82 across scales and a Total EF Summary Score of .82). Validity of the scale was evidenced in numerous analyses (Barkley, 2012). In the dissertation study $\alpha = .93$. (Appendix I)

PROMIS-Depression-Parent/Guardian of Child Age 6-17-Short Form 11 item parent-report survey answered on 5-point Likert scale ranging from 1 (never) to 5 (almost always) assessing adolescent depressive symptoms from parent's perspective. **Higher scores indicate more parent perceived depressive symptoms in their child (score range 11-55).** It is a well-established assessment tool in adolescents with and without special health care needs (DeWalt, et al., 2015; Schalet, et al., 2016; Verchota & Sawin, 2016). In the dissertation study $\alpha = .94$. (Appendix I)

STAR$_x$-P Transition Readiness Questionnaire − parent version 18 items total; parent perception of 3-domains: child's health knowledge, child's health communication and planning, and child's HSM behaviors are rated on a 5-point Likert scale on six factor-based items: disease knowledge, medication management, adult health responsibilities, provider communication,

engagement during appointments, and resource utilization. Scores range on each item from 1 (never, very hard, or nothing) to 5 (always, very easy, a lot), and additional selection of "Not needed for my child's care" as a score of 0. Each item is scored individually and worth a maximum of 5 points. Health Knowledge subscale score range from 0-15, Health Communication & Planning subscale score range from 0-30, and HSM Behaviors subscale range from 0-45. Subdomain scores can be combined to create a total score, ranging from 0 – 90. **Higher total scores reflect greater parent perception of the child's health knowledge (3 items), communication and planning skills (6 items), and engagement in HSM behaviors (9 items)**. Internal reliability is moderate to good for youth with special health care needs (α = 0.545–0.759) (Nazareth, et al., 2018). In the dissertation study: Health Knowledge α = .75, Health Communication/Planning α = .83, HSM Behavior α = .72. (Appendix B)

General Self-Efficacy Scale – parent version 10 item questionnaire used to assess parents' perspective of their adolescent child's confidence in ability to influence health outcomes. Responses are made on a 4-point Likert scale (1 = not true at all, 2= hardly true, 3 = moderately true, 4= exactly true) to items such as "My child can always manage to solve difficult problems If he/she tries hard enough." The total General Self-Efficacy score is calculated by summing all item scores. Total score ranges from 10 to 40. **Higher score indicates more parent perceived self-efficacy in their child.** Internal reliability subscales Cronbach's alphas range from 0.76 to 0.90 in youth with special health care needs. Self-efficacy has been correlated with optimism, work satisfaction, negative coefficients for depression, emotion, stress, anxiety, health complaints, and burnout (Schwarzer & Jerusalem, 1995; Cramm, Strating, Roebroech, & Nieboer, 2013). In the dissertation study α = .80. (Appendix C)

AIR Self-determination Scale – parent version 24 items; parent-report survey answered on 5-point Likert scale ranging from 1 (never) to 5 (always) and assesses child's capacity and opportunity for self-determination. Both a Capacity and Opportunity subscale score can be calculated, as well as a total self-determination score. Questions regarding the adolescent's knowledge, ability, and perception of self-determination behaviors is captured by the Capacity subscale. The Opportunity subscale consists of questions regarding the opportunity the child has to engage in self-determination behaviors at home. Scale was demonstrated to have adequate reliability and validity when measuring self-determination in children with and without ASD (Chou, Wehmeyer, Shogren, Palmer, & Lee, 2017; Shogren, et al., 2008). In the dissertation study $\alpha = .91$. (Appendix D)

Social Facilitation

To explore social facilitation between the adolescent with ASD and their parent, the adolescent with ASD was asked, "*What does your parent do to help you learn how to manage your health?*" Parents were asked, "*What do you do to help your child learn how to self-manage their health?*" Since social facilitation is a process of HSM behavior transition from parent to the adolescent, adolescents were asked about their participation by asking the adolescent, "*What do you do on your own to take care of your health?"* These investigator-developed questions were followed by dropdown menu options commonly found across all chronic health conditions (Ryan & Sawin, 2009) and an optional free-text space was offered to elaborate on responses (see Appendix I). To measure parents perceived barrier(s) to transitioning health responsibility to their child, the following question was asked, "*What are your barriers to teaching your child how to self-manage their health?*" A dropdown menu offered common barriers for parents

transitioning their child to adult services (Reed-Knight, Blount, & Gilleland, 2014). Again, an optional free-text space was offered for parents to elaborate on their responses (Appendix J).

PROCEDURE

Following IRB approval, when contacted by prospective study participants, the PI screened participants for eligibility based on the Eligibility Checklist (Appendix K). All eligible parents of participants were provided an email including study process expectations and a copy of the parent consent (Appendix L) and adolescent assent/consent (Appendix M) forms to review, ask questions, and keep for their records. As indicated in the IRB approved consent/assent forms, all participants were offered the option to complete a hard copy of the survey, in-person, if so desired. Given the diversity of needs within the ASD population, participation in the study may depend on additional assistance (e.g., questions read aloud, accessing the survey, clarification of meaning). To avoid limiting the study to only participants able to independently access and complete the study online, the option of completing the study with the PI present was offered. The PI received IRB approval to provide support in completing the survey, when needed. Parents and adolescents were made aware of this optional support via consent/assent and during the screening process and informed that this support was limited to answering questions, adding additional clarity, and reading questions aloud to assure undue bias. The PI offered to meet the participant at a site of their choosing where the survey could be completed via online or hard copy.

During the screening process, the PI reinforced with parents that the adolescents had to answer survey questions for themselves, so parents were not allowed to be proxy respondents for their children. Parents/caregivers were asked for an email address for their child. When agreed to by parents, the adolescent consent/assent form and survey link were sent directly to the

adolescent's email address. Understanding was provided that the adolescent having their own email address was not a requirement to be a participant in the study and we could move forward with only the parents email address if both parties were more comfortable with this decision. For adolescents over 18 years old, parent/caregiver was asked about legal guardianship of the adolescent and legal permission for participation was obtained as appropriate. A second email to parent/caregiver and adolescent provided the link to the Qualtrics survey where consent/assent forms were posted at the beginning of the survey. Parents needed to select "yes" to agreeing to be a participant in the study and "yes" to agreeing for their child to be in the study before background information survey questions began (Appendix F). Adolescent surveys also led with the adolescent consent/assent form and the adolescent needed to select "yes" agreeing to be in the study before survey questions began. Surveys were designed to be clear, concise, and completed at a time of participants choosing. Additionally, IRB approval was granted November 8, 2019 to allow distance support (phone, Facetime, Skype, Zoom, etc.). When the COVID-19 pandemic reached Texas, distance support became the only option when additional support was needed due to IRB and social distancing restrictions.

Despite several parents initially inquiring about possible additional support for their child and being supplied with direct PI contact information and availability, no additional parent or adolescent support was requested in completing the survey. However, there were two instances where parents voiced their belief in their child's inability to complete the survey despite additional assistance and withdrew from the study before receiving the survey. In other cases, after expressing interest in being a participant and receiving screening questions and study information, no other contact was received despite follow-up inquiries from the PI. It is unknown in these cases, if the perspective participant changed their mind about being in the study, foresaw

a barrier to participating in the study, or their child was uninterested in participation. In total, there were 322 inquiries made about the study. Despite posting the flyer only within agencies and organizations supporting individuals with ASD, three separate cyber-attacks consisting of fraudulent and computer-generated mass inquiries occurred. These "non-legitimate" responses became apparent to the PI based on identified patterns such as report of same secondary contact number that resulted in the same digitized answering machine when called, basic grammatical errors (use of last name in place of first name), patterns in inquiring gmail account addresses, etc. This made up the bulk of study inquiries (226). There were 96 "legitimate" parent or adolescent inquiries made, which resulted in the 40 adolescent/parent dyads represented in this study.

All participants were assigned an individual participant identification number upon meeting inclusion criteria and expressing interest in being in the study. This identification number was used throughout data analysis and dissemination. Dyads were given identification numbers that paired their data (e.g. 101A (adolescent) and 101P (parent). No actual names were ever linked to the study data unless a form of the participants name was given in their supplied email address where their link to the Qualtrics survey was sent. However, these email addresses were removed from the SPSS data. This study was conducted online and outside of a research setting, IRB approval was sought and granted for a Waiver for Documentation for Informed Consent. When they linked to the Qualtrics survey, parents and adolescents were given the option to select "yes" (agreeing to be in the study and questions began) or "no" (exiting the study). Therefore, consent/assent was assumed with the continuation to answer study questions since participants had the option to withdraw from the study and exit at any time. No digital or hard copies of signed informed consent/assent were supplied or stored.

Fieldnotes, audit trail documents, content analysis documentation with coded link and Qualtrics data sets have all been kept in locked files only accessible to the PI. Participant progress was checked weekly via Qualtrics review and noted in the Recruitment Log (Appendix N). To avoid lost responses and confusion accessing the survey, participants were encouraged to complete the survey at one time. For participants not promptly completing the surveys, a friendly reminder email was sent via the participant's stated contact preference at weeks two and four post enrollment. Following six weeks post enrollment, if no progress was made in completing the survey, a final attempt at contacting the participant was made. If still no progress or contact was made, it was assumed that the participant had withdrawn from the study. Logs detailing recruitment activities (eligibility checklist, completion of surveys, pending surveys, reminder emails sent, etc.) were kept by PI. A consort table of study retention is provided (Appendix O).

An unexpected development of study recruitment was parents of multiple children meeting inclusion criteria wanting to participate. Four adolescent/parent triads were included in this study. Parents completed a separate survey for each of their children (labeled e.g. 100P1 and 100P2), which was tracked by identifying the adolescent siblings separately (e.g. 100A1 and 100A2 respectively). To avoid violating the assumption of separate independent data points (i.e., the same parent appearing twice in the data set), the data for both parent and adolescent was examined for missing data and the most complete dyad data set was selected for this study. When both sets of data were equally complete, the included dyad data was selected at random.

Upon completing the survey as described, disbursement of incentives for the participants time and energy took place. Incentives were paid virtually via $25 Amazon gift card to each participant ($25 for adolescent and $25 for parent = $50 per family, except when multiple children were involved then $25 for each adolescent and $25 for parent = $75 per family).

MEASURES AND DATA ANALYSIS

All data were analyzed using IBM SPSS Statistics (*v.* 26.0). Parent data were linked to their child's data by merging the parents' data with the child's data. Data were checked by a second observer to assure accuracy. A preliminary analysis was conducted to assess for missing data, establish descriptive characteristics of the sample, and estimate internal consistency reliability (Cronbach alphas) for all instruments. Cronbach alpha coefficients for all measures except adolescent scores on the subscale health knowledge (alpha =.69) and HSM behavior (alpha =.65) were above .70. Except for the self-efficacy and depressive symptom measures not completed by one adolescent, all survey items had less than 4% missing data and what was missing appeared to be at random. The limited data missing at random was replaced with the average of the values of the parameter estimates derived from multiple imputation samples (average the values of the parameter estimates across the imputation samples). Statistical significance criterion was set at $p \leq .05$.

Adaptation to Measures

Some of the study measures have not been previously used in research involving adolescents with ASD. Most of the measures performed as expected and at acceptable alpha levels (above .7). However, a few adaptations to the instruments had to be made. The rating of the AQ-10 measure was adjusted to reflect autism symptomology as a continuum instead of categorical rating as proposed by the measure's author. The AQ-10 was originally used to flag autism symptomology of concern for follow-up referral and testing. In this study, the intent was to create a total score that would reflect increased autism symptomology. Therefore, parents rated each item on a 4-point scale, reflecting a continuum from Definitely Agree to Definitely Disagree. The opportunity scale score and total scale score of the AIR Self-Determination Scale

were adapted to be relevant for all adolescent participants and not just those currently attending school by dropping the Opportunity at School score and only including Opportunity at Home scores for both adolescent and parent measures.

The Stages of Change-short form, intended to capture the adolescent's perspective of their current level of readiness for HSM, did not produce the expected hierarchical response pattern. This measure was originally intended to capture the readiness level of adults wishing to engage in physical fitness and was adapted to reflect engagements of HSM behaviors in adolescents with ASD. The subjective nature of items may have led to some confusion in question interpretation. Therefore, the following item-by-item descriptive result is offered instead of a total descriptive level score. Most adolescents in the study (83%) reported that in the last month they actively were trying to take care of their health. In the past month, many of the adolescents (63%) stated that they were actively trying to learn how to take care of their health. Adolescent participants (78%) reported they were seriously considering trying to take care of their health or learn about their health in the next six months and many (80%) of the adolescent's also reported they have been taking care of their health for more than six months. Because a meaningful overall score could not be calculated, this measure was not used in subsequent data analysis.

Data Analysis

The adolescent depressive symptom measure provided a total raw score for 14 items ranging from 14 to 70. The parent depressive symptom measure provided a total raw score for 11 items ranging from 11 to 55. Note that the adolescent depressive symptom measure contained three more items than parent version of the measure. These raw scores were converted to T-scores based on a conversion table provided by the PROMIS Health Organization and PROMIS

Cooperative Group for these scales (PROMIS Health Organization (PHO), 2021). An interpretation of the T-scores in relation to depressive symptom severity was also supplied by PROMIS and utilized to support results in this study. Using the provided T-scores allowed adolescent and parent scores to be compared despite the total item and resulting raw score discrepancy.

Paired-samples t-tests were conducted to examine differences in dyad measures completed by both adolescent and parent (depressive symptom, health knowledge, health communication-planning, self-efficacy, self-determination, and HSM behavior). Independent *t* tests and one-way between-subjects ANOVA were conducted to compare demographic variable effect on adolescent HSM behavior.

To test relationships between adolescent and parent variables, bivariate and multivariate statistical analyses using both adolescent and parent rating of the adolescents HSM behavior score were examined. Preliminary analyses showed the relationships to be linear with most of the variables being normally distributed, as assessed by Shapiro-Wilk's test (Adolescent Measures: self-management $p = .268$, communication/planning $p = .457$, PROMIS $p = .260$, self-efficacy $p = .292$, and self-determination $p = .241$; Parent Measures: self-management $p = .894$, communication/planning $p = .398$, depressive symptom $p = .186$, self-efficacy $p = .580$, self-determination $p = .932$, executive functioning $p = .523$, and complexity of ASD $p = .065$). However, violations in normal distribution were noted for both adolescent ($p = .012$) and parent ($p = .001$) health knowledge measures. Additionally, a limited number of outliers (1-2) were found to exist in the adolescent self-efficacy, adolescent health knowledge, parent health knowledge, and ASD complexity measures. Because of the small sample size outliers were not removed. Due to these violations, Kendall’s Tau, non-parametric correlation suitable for smaller

sample sizes and smaller values was examined. Although the actual values for parametric versus non-parametric findings were slightly different, whether relationships were statistically significant or not did not change.

A special form of multiple linear regression analysis, called hierarchical linear regression, was selected to address the variance of HSM behavior explained by process variables asked in research question 1.3. This analysis allows one or more variables to be added to the regression model in separate steps called "blocks". This allows the researcher to "control" for known predictor variables (contextual variables) and identify if adding new variables (process variables) improves a model's ability to predict HSM behavior (Field, 2013).

PROTECTION OF HUMAN SUBJECTS

Institutional Review Board (IRB) approval was received from the University of Texas at Austin IRB on October 24, 2019, prior to any recruitment of study participant to assure protection of human subjects. All study participants received a thorough explanation of study procedures, as well as potential benefits and risks in partaking in the study. All potential study participants were allowed time to ask questions or clarifications prior to obtaining study informed consent or verbal informed assent for participants younger than 18 years or over 18 years when having legal guardianship. Only after study participants (adolescent with ASD and their parent) received a copy of the informed consent or documentation of assent, did data collection proceed. All participants were made aware that participation in the study was voluntary and they could withdraw from the study at any time without penalty.

PRIVACY AND CONFIDENTIALITY OF PARTICIPANTS AND DATA

Privacy and confidentiality of participants was maintained throughout the study process. Participant information was kept private to the full extent allowed by the research process. A

participant number was assigned and used throughout data analysis and study dissemination. No actual names appeared anywhere other than if included on provided email address. However, this email address was only used to send the link to the survey and was not attached to the survey data. No digital or hard copy of signed informed consent or assent documents were retained in keeping with the IRB approval of Waiver of Documentation. All collected online demographic and survey data is stored in a locked file with only a coded link available to the investigator. Any identifying information appearing in the data were removed to assure anonymity of participant.

Potential Benefits and Risks

There are no direct benefits to participants in this dissertation study. Adolescent participants received a $25 incentive, and their parent received a $25 incentive for their participation in this study as a token of appreciation for their time and energy after participants completed their survey. Participants did not incur any costs for their participation except time to participate. Participants gained from contributing to the existing knowledge base and may gain some benefit from sharing their information to the autism community, health care community, and other individuals and families impacted by ASD.

Chapter Summary

This chapter details the methodology used in this cross-sectional descriptive correlational survey study to determine the associations between variables in contextual and process domains and HSM behaviors in adolescents with ASD. The setting, sample selection inclusion and exclusion criteria are presented. Data procedures, participant confidentiality, and potential benefits and risks are discussed. The conceptual measurements and instrument psychometric properties of the survey are described. Lastly, the data analysis procedures to answer the study research questions were summarized.

Chapter 4: Results

This chapter presents the results of this dissertation study. This chapter presents the demographic characteristics of the sample (N = 40 dyads) and finishes by addressing each specific research question posed by the study. The purpose of this descriptive correlational research was to examine factors contributing to HSM behaviors in adolescents with ASD. Adolescents having a diverse set of needs and abilities and their parent/caregiver (40 dyads) each completed an online survey. Since most of the parent/caregiver sample (98%) are parents of the adolescent in the study (only one aunt) the parent/caregiver sample is referred to as the parent sample for the remainder of the study.

SAMPLE

Characteristics of the sample are summarized in Table 3. The mean age of adolescent participants (15.83 years) was slightly skewed (skewness = .73, SE = .37) toward the younger age of the sample with half (50%) being aged 12 to 14 years. This sample comprised more male (75%) versus female (22.5%) adolescent participants, which aligns with ASD diagnosis being four times higher for boys than girls. Most adolescent participants in the sample have at least one comorbid health condition (83%) that mildly to significantly impacts their daily lives (70%). Of the comorbid health conditions reported anxiety was the highest rated mental health condition (63%), GI disorders were among the highest rated physical health condition (23%), and IDD was the highest rated developmental health condition (13%). The median age for ASD diagnosis was 5.0 years with a mean of over nine years (9.38) since diagnosis. Parent participants were primarily White (85%), non-Hispanic (83%) educated mothers who were married (78%). Most parent participants (90%) reported having access to family-centered care and either private

and/or public health insurance (93%). Most of the sample (63%) reported annual household incomes above $75,000.

Table 3. Demographic variables of adolescent and parent participants

Characteristics	Parent N = 40			Adolescent N = 40		
	N (%)	M (SD)	Md/Range	N (%)	M (SD)	Md/Range
Age (years)		47.93 (7.07)	47.0/34-64		15.83 (3.25)	14.5/12-22
12-14 years				20 (50)		
15-18 years				9 (22.5)		
19-22 years				11 (27.5)		
Number Children in Household		2.24 (1.01)	2.0/1-5			
1	6 (24)					
2	10 (40)					
3	7 (28)					
≥4	2 (8)					
Number Children with ASD		1.23 (0.53)	1.0/1-3			
1	33 (82.5)					
≥2	7 (17.5)					
Age ASD Diagnosis					6.45 (4.00)	5.0/1-14
Years Since Diagnosis					9.38 (5.18)	8.5/1-19.5
Gender						
Male	1 (2.5)			30 (75.0)		
Female	39 (97.5)			9 (22.5)		
Other				1 (2.5)		
Race						
White	34 (85)			34 (85)		
Black/African American	1 (2.5)			1 (2.5)		
Asian	1 (2.5)					
Mixed Race	4 (10)			5 (12.5)		
Ethnicity						
Non-Hispanic	33 (82.5)			33 (82.5)		
Hispanic	7 (17.5)			7 (17.5)		
Marital Status						
Married	30 (75)					
Widowed	1 (2.5)					
Separated	3 (7.5)					
Remarried	1 (2.5)					
Divorced	4 (10)					
Never Married	1 (2.5)					

Annual Household Income				
$25,000 or less	5 (12.5)			
$25,001 to $50,000	5 (12.5)			
$50,001 to $75,000	5 (12.5)			
$75,001 to $100,000	9 (22.5)			
$100, 001 or above	16 (40)			
Adolescent lives with				
Both mother and father	28 (70)			
Mother only	8 (20)			
Shared custody	2 (5)			
Two mothers	1 (2.5)			
Aunt and Uncle	1 (2.5)			
Mother's Education				
Did not complete HS	2 (5)			
High school diploma	2 (5)			
Some college/post-HS	15 (37.5)			
College/baccalaureate	15 (37.5)			
Post-baccalaureate	6 (15.0)			
Father's Education				
Did not complete HS	4 (10)			
High school diploma	11 (27.5)			
Some college/post-HS	7 (17.5)			
College/baccalaureate	13 (32.5)			
Post-baccalaureate	5 (12.5)			
Adolescent Current Grade			9.82 (2.67)	9.0/6-15
6		4 (10)		
7		3 (7.5)		
8		10 (25)		
9		4 (10)		
10		5 (12.5)		
11		2 (5)		
12		2 (5)		
13 HS graduate/diploma		5 (12.5)		
14 Some College/degree		5 (12.5)		
Access Family Centered Care				
Yes	36 (90)			
No	4 (10)			
Adolescent Has Health Condition				
Yes		33 (82.5)		
No		7 (17.5)		
Daily impact of Health Condition				
Rarely or not at all		12 (30)		
Sometimes		11 (27.5)		
Usually/or often		9 (22.5)		
Always		8 (20)		

Health Condition (parent report)		
Seizures		2 (5)
GI Disorder		9 (22.5)
Diabetes		1 (4)
Anxiety		25 (62.5)
ADD/ADHD		19 (47.5)
Depression		9 (22.5)
OCD		5 (12.5)
Bipolar Disorder		1 (2.5)
IDD		5 (12.5)
Cerebral Palsy		2 (5)
Other		5 (12.5)
Health Insurance Coverage		
Public	15 (37.5)	
Private	17 (42.5)	
Both public and private	5 (12.5)	
Uninsured	3 (7.5)	

Abbreviations: ADD/ADHD, attention-deficit disorder/ attention-deficit hyperactivity disorder; ASD, autism spectrum disorder; GI, gastrointestinal; HS, high school; IDD, intellectual disability disorder; OCD, obsessive compulsive disorder

RESEARCH AIMS AND QUESTIONS

This dissertation study had three specific aims: 1) Explore what factors are associated with engagement in HSM behavior among adolescents (age 12-22 years) with ASD, 2) Compare adolescent and parent perspective of the adolescent's health process variables and health behavior, and 3) Examine the nature of social facilitation between adolescents with ASD and their parents to enhance the adolescent's HSM behaviors. The following section describes the findings and specific analyses used to address each aim.

How do adolescents with ASD and their parent rate the adolescent's engagement in HSM behaviors?

Descriptive statistics were used to analyze means and standard deviations of adolescent HSM variables reflected in adolescent and parent measures and presented in Table 4. Contextual domain variables were normally distributed (non-significant skewness and non-significant kurtosis) and yielded fair to strong internal consistency on measures [AQ-10 (α = .77), Special

Health Care Assessment (α = .91), Barkley Deficits (α = .93), PROMIS adolescent (α = .91), PROMIS parent (α = .94)]. Although non-significant, the Special Health Care Assessment was the most non-normally distributed of the contextual domain variables (skewness = -.62, SE = .37 and kurtosis = -.93, SE = .73). However, this is likely due to the skip pattern nature of the measure (yes/no branching).

Process domain measures for parents produced good to strong internal consistency [Health Knowledge (α = .89), Health Communication/Planning (α = .83), Self-Efficacy (α = .80), Self-Determination (α = .91)]. Of the parent process domain measures, only health knowledge was non-normally distributed ($p < .05$) with skewness of -.93 (SE = .37) and kurtosis of .55 (SE = .73). Outside of the poor alpha score for adolescent health knowledge (α = .69) measure previously discussed, other process domain measures for adolescents produced fair to good internal consistency [Health Communication/Planning (α = .71), Self-Efficacy (α = .76), Self-Determination (α = .88)]. The health knowledge measure was the only non-normally distributed ($p < .01$) measure for adolescent process domain variables with skewness of -1.01 (SE = .37) and kurtosis of 1.88 (SE = .73).

The single outcome domain measure for both parent (α = .72) and adolescent (α = .65) was HSM behavior. Both parent [skewness = -.16 (SE = .37), kurtosis = -.22 (SE = .73)] and adolescent [skewness -.32 (SE = .37), kurtosis = .47 (SE = .73)] reported scores did not deviate significantly from normality but had a slight left skew.

Table 4. Descriptive Statistics for Parent and Adolescent Measures

Scale/Subscale	Parent (N = 40) M/SD Range/Min-Max	Adolescent (N = 40) M/SD Range/Min-Max
Contextual Domain		
AQ-10	28.73 / 5.13 19-39 / 10-40	
Barkley Deficits in Executive Functioning	54.43 / 13.23 28-80 / 20-80	
Children with Special Health Care Assessment	9.78 / 4.38 0-14 / 0-14	
PROMIS Emotional Distress-Depression-Peds Short Form (T-scores)		55.14 / 9.88 31.70-71.80 / 31.7-86.6
PROMIS-Depression-Parent/Guardian of Child Age 6-17-Short Form (T-scores)	58.08 / 11.11 38.60-79.10 / 32.1-90.5	
Process Domain		
$Star_x$ – Health Knowledge		11.38 / 2.62 5-15 / 0-15
$Star_x$-P – Health Knowledge	12.02 / 2.64 5-15 / 0-15	
$Star_x$ – Health Communication & Planning		18.64 / 4.58 8-29 / 0-30
$Star_x$-P – Health Communication & Planning	17.02 / 5.79 7-28 / 0-30	
General Self-Efficacy Scale	25.23 / 4.34 16-34 / 10-40	27.85 / 4.37 19-40 / 10-40
AIR Self-determination Scale	60.90 / 10.31 40-83 / 18-90	68.21 / 10.13 50-89 / 18-90
Proximal Outcome Domain		
$Star_x$ – Health Self-Management		26.40 / 5.71 11-37 / 0-45
$Star_x$-P – Health Self-Management	25.18 / 6.39 10-38 / 0-45	
(N = 39) for Adolescent PROMIS and General Self-Efficacy measures		

What are the bivariate relationships among the independent variables (background characteristics, adolescents' health condition, complexity of ASD, learning/cognitive ability, capacity to self-manage, health knowledge, self-efficacy, health communication/planning, and self-determination) and the adolescent and parent rating of the dependent variable (adolescents' HSM behavior)?

Bivariate correlational statistics were used to answer this question. Correlations among adolescent and parent measures of demographic characteristics and the adolescents' health complexity, ASD complexity, learning/cognitive ability, depressive symptoms, health knowledge, health communication/planning, self-efficacy, and self-determination and the adolescents' HSM behaviors are shown in Tables 5 and 6.

The aim of this study is to examine adolescent and parent factors contributing to adolescent HSM behavior. Therefore, data analysis of adolescent HSM behaviors revealed a moderate positive correlation with parents' marital status [$r(38) = .48$, $p = .002$], meaning adolescents reported higher HSM behavior scores when parents were married. Moderate positive correlations were also noted for age at ASD diagnosis [$r(38) = .31$, $p = .05$], family income [$r(38) = .35$, $p = .03$], and health knowledge [$r(38) = .37$, $p = .02$]. A strong relationship was revealed with the parent rating of adolescent HSM behaviors [$r(38) = .72$, $p < .001$]. No other significant relationships were noted between adolescent rating of HSM behavior and other demographic variables, or measures completed by the adolescent. However, this is an explorative study and therefore other significant associations between adolescent measures are shown in Table 5. For example, there were associations between parents' marital status and adolescent health communication/planning and self-efficacy.

Table 5. Bivariate Correlations among Adolescent Measures (N=40)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16
Contextual Domain																
1. Adolescent Age	1.00															
2. Adolescent Grade	.95**	1.00														
3. Age ASD Diagnosis	-.01	.08	1.00													
4. Years Since Diagnosis	.63**	.53**	-.78**	1.00												
5. Parent Marital Status	.05	.05	.16	-.10	1.00											
6. Family Income	.28	.25	.09	.11	.75**	1.00										
7. Adolescent IDD	.23	.18	-.13	.25	-.16	-.12	1.00									
8. ASD Complexity	.10	.09	-.16	.19	.01	.14	-.02	1.00								
9. Health Complexity	-.13	-.17	.10	-.16	.15	.27	.11	.38*	1.00							
10. EF Complexity	-.32*	-.31	.29	-.43**	-.13	-.25	.13	.29	.54**	1.00						
11. Depressive Symptoms	.10	.07	.16	-.05	-.19	-.004	.16	.07	-.03	.07	1.00					
Process Domain																
12. Knowledge	-.28	-.28	.34*	-.44**	.06	-.15	-.25	-.28	-.10	.08	-.12	1.00				
13. Communication/Planning	.54	.12	.08	-.01	.39*	.22	-.17	-.10	-.08	-.25	-.36*	.27	1.00			
14. Self-Efficacy	-.14	-.12	-.34*	.17	.32*	.19	-.18	.04	-.06	-.24	-.44**	.10	.56**	1.00		
15. Self-Determination	-.12	-.11	-.15	.04	.24	.12	-.17	-.02	.03	-.13	-.42**	.11	.47**	.51**	1.00	
Proximal Outcome Domain																
16. HSM Behavior	.13	.11	.31*	-.16	.48**	.35*	-.30	-.12	-.19	-.17	.05	.37*	.23	-.09	.09	1.00

(N=39) for adolescent depressive symptom and self-efficacy variables *Correlation is significant at the .05 level (2-tailed) **Correlations is significant at the .001 level (2-tailed). Abbreviations: ASD – autism spectrum disorder; IDD – intellectual developmental disability; EF – executive function; HSM – health self-management

Table 6. Bivariate Correlations among Parent Measures (N=40)

Variable	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17
Contextual Domain																	
1. Adolescent Age	1.00																
2. Adolescent Grade	.95**	1.00															
3. Age ASD Diagnosis	-.01	.08	1.00														
4. Years Since Diagnosis	.63**	.53**	-.78**	1.00													
5. Parent Marital Status	.05	.05	.16	-.10	1.00												
6. Family Income	.28	.25	.09	.11	.75**	1.00											
7. Adolescent IDD	.23	.18	-.13	.25	-.16	-.12	1.00										
8. ASD Complexity	.10	.09	-.16	.19	.01	.14	-.02	1.00									
9. Health Complexity	-.13	-.17	.10	-.16	.15	.27	.11	.38*	1.00								
10. EF Complexity	-.32*	-.31	.29	-.43**	-.13	-.25	.13	.29	.54**	1.00							
11. Depressive Symptoms	-.11	-.05	.32*	-.32*	.03	.12	.06	.38*	.33*	.42**	1.00						
Process Domain																	
12. Knowledge	.10	.09	.20	-.10	.17	.06	-.15	-.30	-.25	-.28	-.11	1.00					
13. Communication/Planning	.34*	.28	.03	.19	.23	.21	-.15	-.33*	-.29	-.42**	-.43**	.61**	1.00				
14. Self-Efficacy	.18	.14	-.17	.24	.45**	.26	.02	-.25	-.31	-.43**	-.24	.47**	.54**	1.00			
15. Self-Determination	-.01	-.06	-.12	.09	.25	.17	.07	-.50**	-.23	-.47**	-.50**	.34*	.57**	.54**	1.00		
Proximal Outcome Domain																	
16. HSM Behavior (parent)	.20	.22	.31	-.11	.34*	.19	-.09	-.39*	-.26	-.26	-.11	.64**	.52**	.47**	.38*	1.00	
17. HSM Behavior (adolescent)	.13	.11	.31*	-.16	.48**	.35*	-.30	-.12	-.19	-.17	-.02	.52**	.62**	.46**	.31	.72**	1.00

*Correlation is significant at the .05 level (2-tailed) **Correlations is significant at the .001 level (2-tailed). Abbreviations: ASD – autism spectrum disorder; IDD – intellectual developmental disability; EF – executive function; HSM – health self-management

Also, the higher the adolescents' reported depressive symptoms, the lower their scores on health communication/planning, self-efficacy, and self-determination. Three parent process variables were moderately and significantly associated with the adolescent rating of HSM behavior: health knowledge [$r(38) = .52$, $p = .001$], health communication-planning [$r(38) = .62$, $p < .001$], and self-efficacy [$r(38) = .46$, $p = .003$].

Significant associations were also revealed for parent rating of the adolescents HSM behavior. Moderate to strong associations were found for two contextual domain variable autism complexity [$r(38) = -.39$, $p = .01$] and parents marital status [$r(38) = .34$, $p = .03$], as well as all process domain variables: health knowledge [$r(38) = .64$, $p < .001$], health communication/planning [$r(38) = .52$, $p = .001$] , self-efficacy [$r(37) = .47$, $p = .002$], and self-determination [$r(38) = .38$, $p = .02$]. Other significant associations between parent measures are noted in Table 6. For example, parent scores for their child's process variables tend to be negatively correlated with their child's ASD complexity, executive function deficits, and depressive symptoms.

When comparing adolescent and parent measures for association, moderate to strong relationships were noted for measures of the same type. For instance, a moderate association

Table 7. Bivariate Correlations among Parent and Adolescent Measures (N=40)

Parent Measures	Adolescent Measures					
Variables	1	2	3	4	5	6
Contextual Domain						
1. Depressive Symptoms	.57**	.002	-.19	-.23	-.27	-.02
Process Domain						
2. Knowledge	-.02	.59**	.19	-.11	-.07	.52**
3. Communication/Planning	-.02	.37*	.45**	.10	.20	.62**
4. Self-Efficacy	-.19	.31	.36*	.41**	.23	.46**
5. Self-Determination	-.17	.18	.37*	.22	.51**	.31
Proximal Outcome Domain						
6. HSM Behavior	.02	.31	.21	-.07	.03	.72**
N=39 for adolescent self-efficacy and depressive symptom variables. *Correlation is significant at the 0.05 level (2-tailed) **Correlation is significant at the 0.001 level (2-tailed)						

between parent rating of the adolescent depressive symptoms and the adolescent rating of depressive symptoms was noted [$r(38) = .57$, $p < .001$]. However, moderate associations were also noted between other parent and adolescent measures, particularly between health communication/planning and other measures. For instance, adolescent rating of health communication/planning had a significant positive correlation with parent rating of self-efficacy [$r(38) = .36$, $p = .02$] as shown in Table 7.

How much do adolescent's health care condition knowledge, self-efficacy, ability to communicate with healthcare provider, planning abilities, self-determination, and HSM readiness explain the variance in adolescent's HSM behaviors after controlling for individual and family contextual factors?

The Adolescent Health Self-Management Model was used to guide the identification of contextual and process domain variables. Bivariate correlations between all potential predictor variables and the adolescent's HSM behavior were evaluated. Some demographic variables were dichotomized when appropriate. Parents' marital status was dichotomized to married and remarried/not married due to small sample in some marital categories (divorced/separated, widowed, never married). Parents' marital status (married/remarried vs not married) and adolescent HSM behavior was compared and found to be significant [$t(39) = 3.31$, $p = .006$]. Furthermore, additional comparisons of the parent's marital status (married/remarried vs not married) also suggest significant relationships with adolescent rating of health communication-planning [$t(39) = 2.35$, $p = .04$] and adolescent rating of self-efficacy measures [$t(38) = 2.14$, p = .05]. The distribution of all variables was evaluated independently and determined to meet assumptions (specificity, linearity, normality, and homoscedasticity) required for regression analysis. Potential predictor variables of interest are presented in Table 8.

Table 8. Relationships between Contextual and Process Domain Variables with Adolescent HSM Behaviors (N=40)

Domain	Source	Variable	Mean (SD)	Statistic
Contextual	Background Questionnaire	Adolescent Age (years)		r = 0.13 p = 0.42
	Background Questionnaire	Age at ASD Diagnosis (years)	6.45 (4.01)	r = 0.31* p = 0.05
	Background Questionnaire	Years since diagnosis	9.38 (5.18)	r = -0.16 p = 0.32
	Background Questionnaire	Number Children: 1 2 ≥3	 25.33 (5.21) 25.94 (5.27) 28.50 (6.98)	 F = 0.94 p = 0.40
	Background Questionnaire	Children with ASD 1 ≥ 2	 26.30 (5.94) 26.86 (4.81)	*t* = -0.23 p = 0.82
	Background Questionnaire	Gender: Adol: Male (n = 30) Female (n = 9) Prnt: Male (n = 1) Female (n = 39)	 25.87 (5.85) 27.67 (5.41)	 *t* = 0.82 p =0.42
	Background Questionnaire	Race: Adol: White (n = 38) Non-White (n = 2) Prnt: White (n = 38) Non-White (n = 2)	 28.00 (5.09) 22.50 (2.12) 26.67 (5.84) 23.00 (1.73)	 *t* = 1.49 p = 0.15 *t* = 2.65 p = 0.03
	Background Questionnaire	Ethnicity: Adol: Hispanic (n = 7) Non-Hispanic (n = 33) Prnt: Hispanic (n = 7) Non-Hispanic (n = 33)	 26.58 (6.19) 25.57 (2.51)	 *t* = 0.70 p = 0.49
	Background Questionnaire	Parent marital status: Married/remarried (n = 31) Non-married (n = 9) **Other significant:** Comm/Plan Married/remarried Non-married Self-Efficacy Married/remarried Non-married	 27.87 (5.00) 21.33 (5.27) 19.60 (4.07) 15.34 (4.97) 28.60 (4.27) 25.33 (3.94)	 *t* = 3.31 p = 0.006** *t* = 2.35 p = 0.04* *t* = 2.14 p < 0.05*
	Background Questionnaire	Adolescent lives/w: Mother & Father (n = 28) Other (n = 12)	 27.14 (5.52) 24.67 (6.01)	 *t* = 1.27 p = 0.21

	Background Questionnaire	Mother's education: Not complete HS (n = 2) Complete HS (n = 2) Some college (n = 15) Baccalaureate (n = 15) Post-baccalaureate (n = 6)	 22.50 (7.78) 25.50 (.71) 26.67 (5.19) 28.07 (5.27) 23.17 (7.83)	 F = 1.06 p = 0.39
	Background Questionnaire	Father's education: Not complete HS (n = 4) Complete HS (n = 11) Some college (n = 7) Baccalaureate (n = 13) Post-baccalaureate (n = 5)	 22.00 (3.92) 25.18 (6.75) 27.43 (2.57) 28.15 (6.40) 26.60 (4.93)	 F = 1.09 p = 0.38
	Background Questionnaire	Adolescent grade: Middle School (n = 17) High School (n = 13) Post-High School (n = 10)	 26.53 (4.89) 25.31 (7.03) 27.60 (5.44)	 F = 0.45 p = 0.64
	Background Questionnaire	Health condition Yes (n = 33) No (n = 7)	 26.57 (5.67) 25.57 (6.27)	*t* = -0.42 p = 0.68
	Background Questionnaire	Adolescent IDD Yes (n=5) No (n=35)	 22.00 (3.39) 27.03 (5.73)	*t* = -2.80 p = 0.02*
	Background Questionnaire	**Other Significant:** Adolescent depression Yes (n=9) No (n=31) Adolescent having OCD w/ Self-Efficacy Yes (n=5) No (n=35)	 40.50 (9.19) 31.58 (11.19) 24.20 (3.11) 28.38 (4.31)	 *t* = -2.33 p = 0.04* *t* = 2.65 p = 0.04*
	Background Questionnaire	Health insurance: Public (n = 15) Private (n = 17) Public and Private (n = 5) Uninsured (n = 3)	 25.67 (3.64) 27.18 (7.29) 24.80 (6.18) 28.33 (4.51)	 F = 0.41 p = 0.75
	Background Questionnaire	HH income: < 25,000 (n = 5) 25,000-50,000 (n = 5) 50,001-75,000 (n = 5) 75,001-100,000 (n = 9) >100,000 (n = 16)	 24.20 (5.63) 21.80 (7.66) 26.40 (4.83) 26.56 (4.50) 28.44 (5.53)	 *r* = 0.35* p = 0.03
	Background Questionnaire	HH income: ≤ 100K (n = 24) >100K (n = 16)	 25.04 (5.53) 28.44 (5.53)	 *t* = -1.90 p = 0.07
	Background Questionnaire	Health affect: Rarely (n = 12) Sometimes (n = 11) Usually (n = 9) Always (n = 8)	 26.83 (5.22) 27.09 (4.89) 26.67 (7.07) 24.50 (6.50)	 F = 0.36 p = 0.78

	Background Questionnaire	Access FCC: Yes (n = 36) No (n = 4)	 27.26 (6.05) 26.25 (4.99)	 *t* = -0.32 p = 0.75
	AQ-10	ASD complexity	28.73 (5.13)	r = -0.12 p = 0.45
	SHCN Assessment	Health complexity	9.78 (4.38)	r = -0.19 p = 0.25
	Berkley EF Scale	Learning/cognitive ability	54.43 (13.23)	r = -0.17 p = 0.29
	PROMIS	Depressive symptoms	Parent 58.08 (11.11) Adolescent 55.14 (9.88)	r = -0.02 p = 0.92 r = 0.05 p = 0.77
Process	$Star_x$	Skill: Knowledge	Parent 12.62 (2.64) Adolescent 11.38 (2.62)	r = 0.52** p = 0.001 r = 0.37* p = 0.02
	$Star_x$	Skill: Communication and planning	Parent 17.02 (5.79) Adolescent 18.64 (4.58)	r = 0.62** p < .001 r = 0.23 p = 0.16
	General SE Scale	Belief: Self-efficacy	Parent 25.23 (4.34) Adolescent 27.85 (4.37)	r = 0.46** p = 0.003 r = -0.09 p = 0.58
	AIR SD Scale	Ability: Self-determination	Parent 60.90 (10.31) Adolescent 68.21 (10.13)	r = 0.31 p = 0.05 r = 0.09 p = 0.60

N = 39 adolescent depressive symptom and self-efficacy measures
*Correlation is significant at the 0.05 level (2-tailed) **Correlation is significant at the 0.001 level (2-tailed)
Abbreviations: EF = executive function; FCC = family centered care; IDD = intellectual developmental disorder; HH = household; SD = self-determination; SE = self-efficacy Adol = adolescent; Prnt = parent

Table 9. Hierarchical Regression Analysis Predicting HSM Behavior with Adolescent Variables (N = 39)

		B	SE	β	t	*p*	Adjusted R^2	*p*	ΔR^2	*p*
Step 1	Parent marital status[a]	7.04	1.85	0.52	3.81	0.001	0.32	0.001		
	Adolescent EF (deficits)	-0.11	.06	-0.26	-1.96	0.058				
	Age at ASD Diagnosis	0.19	0.23	0.13	0.83	0.410				
Step 2	Health Knowledge	0.76	0.29	0.35	2.59	0.014	0.43	<.001	0.13	0.02
	Adolescent Self-Efficacy	-0.41	0.19	-0.31	-2.10	0.043				

Abbreviations: EF, Barkley Executive Functioning; $Star_x$, Self-report transition readiness questionnaire.
a. Variable dichotomized as 0=Parents not married, 1=Parents married/remarried

Criteria for inclusion consideration included those variables having the highest bivariate correlation (above .30) with adolescent HSM behavior, those with evidence of internal consistency reliability, and those with minimal or no missing data which included: adolescent age at ASD diagnosis, complexity of ASD, parent marital status, family income, health knowledge, health communication/planning, self-efficacy, and self-determination. The adolescents' executive function was examined due to moderate association with other variables.

Due to small sample size, three contextual domain variables (parents' marital status, adolescent age at ASD diagnosis, adolescent executive function deficits) and two process predictor variables (health knowledge and self-efficacy) were included in the two-step hierarchical regression analysis. The adolescents HSM behavior score was used as the dependent variable in the hierarchical regression analysis. The model of best-fit is presented in Table 9.

In "block" one of the model contextual variables explained 32% [Adj. R^2 = .32, $F(3, 35) = 6.97$, $p = .001$] of the variance in adolescent HSM behavior. After entry of process variables in "block" two (health knowledge and self-efficacy) an additional 11% [$R^2 = .13$, $F(2, 33) = 4.44$, $p < .001$] of the variance was explained. In this final model, three of the five predictor variables were significant: parents' marital status [$b = .52$, $t(38) = 3.81$, $p = .001$], health knowledge [$b = .35$, $t(38) = 2.59$, $p = .01$], and self-efficacy [$b = -.31$, $t(37) = -2.10$, $p = .04$]. When process domain variables were added, executive function approached statistical significance as a predictor ($b = -.26$, $t(38) = -1.96$, p = .058). Adolescent age diagnosed with ASD was significant in step 1 but became non-

significant in step 2. The results indicated that the model accounted for a statistically significant amount of variance in HSM behavior, $F(5,33) = 6.78$, $p < .001$.

Regression diagnostics indicated that statistical assumptions were met for hierarchical regression analyses. Analysis of standard residuals was examined and showed that the data contained no outliers (Standard Residual Minimum = -2.63, Standard Residual Maximum = 1.63). Assumption of collinearity tests of the data indicated that multicollinearity was not a concern (Parent marital status, Tolerance = .80, VIF = 1.25; Executive Function Deficit, Tolerance = .85, VIF = 1.17; Adolescent age at ASD diagnosis, Tolerance = .619, VIF = 1.61; Health Knowledge, Tolerance = .82, VIF = 1.22; Self-Efficacy, Tolerance = .69, VIF = 1.44). Assumption of independent errors for the data was met (Durbin-Watson value = 1.70). The data contained approximately normally distributed errors as indicated by the histogram of standardized residuals and the normal P-P plot of standardized residuals, which showed points that were not completely on the line, but only small deviations from the line. The scatterplot of standardized residuals indicated that the data met the assumptions of homogeneity of variance and linearity. Lastly, the data also met the assumption of non-zero variances (Parents marital status, Variance = .179; Executive Function Deficit, Variance = 175.12; Age at ASD diagnosis, Variance = 16.05; Health Knowledge, Variance = 6.87; Self-Efficacy, Variance = 19.13).

How do adolescent and parent perceptions of the adolescents' contextual and process variables and the adolescents' HSM behaviors compare?

Paired t-test of adolescent and parent reported contextual (depressive symptoms) domain measures and process domain measures (health knowledge, self-efficacy, health communication/ planning, self-determination, and adolescents' HSM behaviors) were used to evaluate differences in adolescent and parent perceptions (Table 10). Differences in adolescent and parent perspective were statistically significant for two of the six comparative measures: self-efficacy and self- determination. Effect sizes for all comparisons (shown as Cohen D values) ranged from .20 to .72.

A Shapiro-Wilk's test showed a significant departure from normality for both self-efficacy (W(39)=.925, p = .012) and health knowledge (W(40) = .930, p = .017) measures, resulting in non-parametric tests being conducted to examine differences in these two scales.

Table 10. Group Differences Between Adolescent and Parent Measures (N = 40)

Measure	Adolescent M (SD)	Parent M (SD)	df	t	p	Cohen's d
Pair 1: Depressive Symptoms	55.14 (9.88)	57.86 (11.17)	38	-1.72	.09	-0.26
Pair 2: Health Knowledge	11.38 (2.62)	12.02 (2.64)	39	-1.70	.10	-0.24
Pair 3: Health Comm/Plan	18.64 (4.58)	17.02 (5.79)	39	1.85	.07	0.31
Pair 4: Self-Efficacy	27.85 (4.37)	25.10 (4.33)	38	3.62	.001**	0.63
Pair 5: Self-Determination	68.21 (10.13)	60.90 (10.31)	39	4.55	<.001***	0.72
Pair 6: Self-Management	26.40 (5.71)	25.18 (6.39)	39	1.68	.10	0.20

N = 39 for adolescent depressive symptoms and self-efficacy measures
****Significant at the 0.001 level (2-tailed) *****Significant at the <0.001 level (2-tailed)**

According to the Wilcoxon Signed Rank Test (measure level, matched groups, and symmetrical distribution assumptions met) showed that adolescent and parent rating of the adolescents' health knowledge did not elicit a statistically significant difference (z = -1.927, p = .054). Indeed, median health knowledge score ratings were 12.02 (parent) and 11.38 (adolescent). A Wilcoxon Signed Rank Test (assumptions met) was conducted on adolescent (M = 27.85, SD = 4.37) and parent (M = 25.23, SD = 4.34) rating of the adolescents' self-efficacy, and found to be significant (z = 3.22, p = .001**). The significant difference for self-efficacy scores [z(38) = 3.22, p = .001] suggests on average that adolescents perceive themselves as having higher rates of self-efficacy than parent perceive.

An examination of parent (M = 60.90, SD = 10.31) and adolescent (M= 68.21, SD = 10.13) self-determination scores indicate the adolescent sample perceived their self-determination to be significantly higher than their parents [t(39) = 4.55, p <.001]. When comparing adolescents (M = 55.14, SD = 9.88) and parent (M = 57.86, SD = 11.17) mean rating on the depressive symptom measure, the finding was non-significant. However, T-scores descriptive statistics were run on the interpreted value of the T-scores and are presented in Table 11. Although about half the adolescents' depressive symptom scores

Table 11. Adolescent Depressive Symptom Rating

PROMIS T-scores	**Adolescent (N=39)**	**Parents (N=40)**
	M SD	**M SD**
None to Slight	21 (54%)	15 (38%)
Mild	4 (10%)	7 (17%)
Moderate	13 (33%)	12 (30%)
Severe	1 (3%)	6 (15%)

fell into the none to slight depressive symptoms range, only 38% of parents' scores of their children's symptoms were in this range.

What do parents do to prepare their child to transition to HSM?

Parents and adolescents were both asked what the parent does to help the adolescent engage in HSM behaviors. Descriptive statistics were used to examine the number and percentage of responses for each category in the pull-down menus provided. These results are exhibited in Table 12. Both adolescents and parents reported parents were most likely to teach the adolescent how to manage their emotions (75% vs 92.5%) and engage in health promoting behaviors (87.5% vs 90%). Parents were more likely than adolescents to report they taught their children how to monitor their health (85% versus 52.5%) and take medication (72.5% versus 55%). Adolescents were more likely to report parents helped them find health information (60% versus 47.5%) and set-up adaptive devices (42.5% versus 25%). Adolescents were twice as likely as parents to report that their parent manages all health care needs (30% versus 15%). The agreement between adolescents and parents was highest for one of the lowest reported teaching aspects, how to set-up doctor's appointments (25%).

Parents and adolescents were given an "other" category they could use to describe additional strategies parents employed to support adolescent HSM behavior. Descriptive content analysis was used to identify additional themes. For instance, a lack of expectation that the adolescent would assume responsibility for their health appeared. Some adolescents stated they were too young to assume health responsibilities, "*I'm 14 so I feel like I'm a bit young*" and "*for a lot of this I'm too young to be able to do this on*

my own, even if I didn't have autism" and *"I like mom to do a lot of doctor stuff"*. Parents also seemed to struggle with this transition. "*I really didn't think of that until answering this survey*". This is reflected by many parent and adolescent reports that the parent is currently managing all health care needs (15% and 30%, respectively).

Table 12. Parent and Adolescent Responses to Social Facilitation Questions (N = 40)

Response	Parent n/%	Adolescent n/%
What parent does to support adolescent HSM behavior		
Nothing – Parent manages all health care needs	6 (15.0)	12 (30.0)
Teaches about medications	29 (72.5)	22 (55.0)
Teaches to talk to doctor	31 (77.5)	24 (60.0)
Teaches to monitor for s/s of illness	34 (85.0)	21 (52.5)
Teaches how to complete a treatment (adolescent only asked)	-	12 (30.0)
Shows how to find information about health	19 (47.5)	24 (60.0)
Shows how to set-up health reminders, timers, etc.	10 (25.0)	17 (42.5)
Teaches to promote health (eat right, exercise, etc.)	36 (90.0)	35 (87.5)
Teaches to manage emotions	37 (92.5)	30 (75.0)
Teaches to set-up doctor's appointments	10 (25.0)	10 (25.0)
Teaches how to report s/s of illness to doctor (parent only asked)	26 (65.0)	-
What adolescent does to take care of own health		
Nothing, parent takes care of all health needs		10 (25.0)
Talk to parent about wanting more responsibility for my health		14 (35.0)
I monitor my health for s/s that I need to contact my doctor		19 (47.5)
I schedule my own appointments with therapist		4 (10.0)
I get enough sleep, eat right, and exercise regularly		21 (52.5)
I use adaptive devices for my health		8 (20.0)
Barriers for parents to teach HSM behaviors		
I never thought of teaching my child to self-manage their health	8 (20.0)	
Too many other competing teaching priorities for my child	11 (27.5)	
Lack of information about what to teach my child	7 (17.5)	
Lack of time	12 (30.0)	
Too many health concerns for my child to self-manage	7 (17.5)	
No support from health care team about how to do this	5 (12.5)	
Too many competing family priorities	17 (42.5)	

Active engagement and collaboration between many parents and adolescent stakeholders in the social facilitation process was the second trend. For example, one

parent stated, "*We're in the process of learning these things and transitioning to more independence*". While another parent stated, "*(Child's Name) always asks questions about medications and treatment*". Still another parent declared, "*I don't teach so much at this point so much as reinforce previously taught lessons*". Parents also made comments about teaching their child to advocate for themselves in the health domain. One parent said, "*I try to encourage her to speak up for herself now that she is a legal adult because no one really cares what her mother has to say now. It's all about her*". Another pattern that seemed to emerge was regarding parent concern for their child transitioning successfully to adult responsibilities. One parent said, "*I am not confident as he reaches adulthood he will manage his health needs adequately*" and another stated, "*There is currently no system outside of Mom to teach him how to self-manage his health*".

There were few parents or adolescents that did not go on to select a health aspect being transitioned to the child, even after selecting that parent manages all child's health care needs. Additionally, a little over half (55%) of parents responded to the free-text option regarding what they teach their child. To gain a better understanding of what aspects parents are teaching their child from these responses, the narratives were examined for social facilitation aspects and categorized as social influence, social support, or negotiated collaboration. From the responses, it was determined that aspects of social support were most expressed (48%), this was followed by negotiated collaboration (35%), then aspects of social influence (28%).

What are adolescents with ASD doing to transition to self-manage their health?

Descriptive statistics were used to describe the number and percentage of responses for each category in the pull-down menu asking adolescents the question, "*What do you do on your own to take care of your health?*" (Table 12). Some adolescents reported they did nothing on their own and relied on parents to manage their health (25%), while other youth sought more involvement (35%). Adolescents most often reported that they took steps to promote good health (52.5%) followed by regularly monitoring their health for signs and symptoms of illness (47.5%) as ways to manage their health. A descriptive content analysis was again used to identify trends or patterns of additional open text responses. One recurring trend appeared from the adolescent responses about seeking independence. For example, one adolescent stated, "*I learn a lot on my own from books and the internet. I currently scribe for a family practice doctor so I've been learning a lot from her too*". Another stated, "*While I may need a reminder or two every so often, I basically take care of my life with an exception being driving*". Others identified a need to take on more responsibility, "*I need to be more active*" and "*I need to do more*".

What do parent perceive as barriers to transitioning their adolescent with ASD to HSM?

Descriptive statistics and content analysis of free-text responses were used to examine parent responses to the question, "*What are your barriers to teaching your child how to self-manage their health?*" Parents most frequently endorsed competing family priorities (42.5%) and lack of time (30%) as barriers to teaching HSM to their children.

For some parents, awareness (20%) or a lack of understanding on what to teach their child were barriers (17.5%). The most prominent theme from parents' additional comments was related to their child's communication difficulties. Statements such as, "*Child has difficulties with expressive verbal communication*" and "*engaging in dialogue can sometimes be cut short if she gets embarrassed or flustered*" - are examples of these comments. While another parent expressed lack of barriers when she stated, "*In some ways my son has an easier time than the rest of us because he likes to follow rules; in other words, when he decided to go gluten free -- he just did it and never cheats whereas the rest of us have more trouble. We wish we had his willpower:-)*". Similar to a few adolescent statements, the adolescent's inability to drive themselves to appointments was of significant concern to some parents regarding their child's self-management ability. Parents stated, "*my daughter cannot drive (too distracted)*" and "*My child doesn't drive so I have to schedule his appts*" and "*Another barrier is my daughter not having a driver's license.*" Some statements indicated parents may be struggling with their own transition as indicated by parent statements such as, "*A big barrier is making time to remember to encourage him to take over tasks rather than doing them for him*" and "*I lack the skill on "how" to let go of that aspect*". Finally, a few parents expressed feelings of exhaustion. This was best stated by one parent who wrote, "*Just straight up overwhelmed. It's hard to remember every little thing I should be doing for my children. It's especially hard to look toward the future and making them independent when we have so much happening in the moment*".

SUMMARY

This chapter provides the findings of a descriptive correlational study aimed at examining variables contributing to HSM behaviors in adolescents with ASD. Guided by the Adolescent Health Self-Management Model, the results provided by this chapter are the first known glimpse of this health transition in adolescents with ASD and contribute to understanding of how key contextual and process domain variables relate to adolescent HSM.

Chapter 5: Discussion

Adolescents with ASD are at increased risk of unmet health care needs that may lead to a life expectancy half that of their typically developing peers (DaWalt, Hong, Greenberg, & Mailick, 2019). Yet, previous research indicates that less than 14% of these youth receive any type of structured health transition services and are half as likely to receive transition services when compared to other YSHCN (Cheak-Zamora, Yang, Farmer, & Clark, 2013). These transition services may improve health outcomes throughout their lifetime (White, et al., 2018). As a result, parents become the predominant guide for the health transition of these adolescents (Reed-Knight, Blount, & Gilleland, 2014). Given the dearth of research examining transition of health responsibility from parent to adolescent with ASD, this study had three specific aims: to explore factors associated with adolescent HSM behavior, compare parent and adolescent perspective in health transition, and examine the nature of social facilitation between parent and adolescent that may contribute to HSM behavior. This chapter provides a summary and discussion of findings addressing the aims of this study, some noteworthy limitations of the study, and finishes with the implications for future practice, research, and policy.

Many characteristics and features of this study sample well align with what is known from existing national data. For instance, in 2017 the U.S. Department of Health and Human Services report to congress titled *Young Adults and Transition Youth with Autism Spectrum Disorder* compared survey data for middle and high school youth with ASD and other disabilities as defined under the Individuals with Disabilities Education

Act. Youth with ASD in that survey of the National Longitudinal Transition Study were more likely than youth with other disabilities to be male (84% versus 67%); less likely to be from socioeconomically disadvantaged families (37% versus 58%); less likely to be Black not Hispanic (12% versus 19%) or Hispanic (16% versus 24%); more likely to have at least one parent with a four-year college degree (43% versus 26%) and have parents who are married (72% versus 63%) (U.S. Department of Health and Human Services, 2017). However, adolescents in this dissertation study sample may differ in their ability level when compared to the youth in the national survey. For instance, youth with ASD when compared to youth with other disabilities were less likely to independently manage activities of daily living (17% versus 46%) and were less likely to have taken a college entrance or placement test (29% to 42%) (U.S. Department of Health and Human Services, 2017). While this was not the focus of this dissertation study, adolescent participants in this study appear to be somewhat independent and are managing at or near academic level.

FACTORS OF HEALTH SELF-MANAGEMENT BEHAVIOR

Research about HSM behavior for adolescents with ASD is relatively absent from the literature. Therefore, the contextual and process domain variables explored in this study were influenced by the nascent research examining health transition in youth with special health care needs. However, from the literature a known barrier to health transition is the lack of clear concepts, relationships, and frameworks guiding health professionals in implementing the health transition process (Betz C. , 2013; Betz, et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). Therefore, the introduction of the

AHSM model used to guide the transition process in this dissertation study may be a substantial contribution to adolescent health transition in general (Lebrun-Harris, et al., 2018). Findings of this study suggest relationships among contextual and process domain variables as they relate to the proximal outcome of reported adolescent HSM behavior. These relationships are explained well by the AHSM model and worthy of closer examination.

Relationships Among Variables

Given the lack of research examining health transition for adolescents with ASD to increase HSM behavior and ultimately improve health outcomes, these results must be considered exploratory at this time. However, a major finding of this study is the relationship of contextual and process variables to HSM behavior. Beginning with contextual domain associations with HSM behavior, a number of adolescent (age at ASD diagnosis, ASD complexity) and family characteristics (parents' marital status, family household income) correlations were found. Demographic variables such as parental divorce, income hardship, and domestic violence have previously been associated with adverse childhood experiences that may significantly contribute to increased unmet health care needs in the ASD population (Berg, Shiu, Feinstein, Msalll, & Acharya, 2018; Karpur, Lello, Frazier, Dixon, & Shih, 2018; Rigles, 2017). While adverse childhood experiences were not measured in this study, this is the first known study to relate potential risk and protective factors to adolescent with ASD reported HSM behavior. Individual and family characteristics such as the ones found in this study are known to impact self-management in other YSHCN, which further supports these relationships for

this population (Betz, et al., 2014; Ryan & Sawin, 2009; Verchota & Sawin, 2016). Among the family characteristics examined here, the one more strongly related to HSM behavior as well as process factors such as self-efficacy, health communication/planning, and self-determination was the parents' marital status, which also had a strong negative correlation with family income.

A moderate positive relationship emerged between HSM behavior and age at ASD diagnosis, suggesting that the older the age at diagnosis, the higher the reported HSM behavior. Along with non-significant relationships between HSM behavior and other adolescent factors (age, grade, years since ASD diagnosis, complexity of health condition) this finding is perplexing. An ASD diagnosis later in age could be indicative of more learned adaptive behavior or fewer challenges relating to the adolescents' autism disorder. This could in-turn reflect on the adolescent's ability to self-manage their health.

Although resilience was not a variable examined in this study, resilience within individual and family factors should be investigated in future studies of HSM behaviors. The only known study of adolescents with ASD exploring health, adverse childhood events, and resilience found a negative association between adverse childhood events, health resilience, and health, but not a direct association between adverse childhood events and resilience (Rigles, 2017). The findings of that study were unlike other studies involving resilience and health in other youth with special health care needs. Adolescents with ASD are at risk of experiencing significantly more adverse childhood experiences when compared to other youth with special health care needs, yet somehow maintain their resilience (Rigles, 2017). In following a social-ecological perspective, it has been

suggested that the daily challenges individuals with ASD face can be viewed as adversities and therefore provide the basis of a conceptual framework in understanding how to improve the well-being of autistic individuals and their families (Lai & Szatmari, 2019). Thus, a better understanding of the role of resilience in adolescents with ASD may be warranted to support those transitioning to HSM behavior.

While many non-significant relationships were found between HSM behavior and other contextual variables, the interrelationship between the parents' report of adolescent's health complexity, executive functioning deficits, and depressive symptoms, may suggest careful assessment of these potential risk factors before considering health transition for adolescents with ASD. It is known that executive function contributes to adolescent planning, organization, problem solving, self-monitoring, and working memory. Given the potential influence of executive function, it is surprising that a non-significant relationship was found between executive function and HSM behavior. This finding is inconsistent with previous transition studies suggesting a strong relationship between executive function and self-management in other youth with special health care needs (Gutierrez-Colina, et al., 2017; Jones, Jacobson, & Tarazi, 2017). Perhaps the fact that adolescent HSM was self-reported could explain why some of the relationships between HSM and other contextual factors were not found in the study. Furthermore, moderate relationships found in this study between executive functioning deficits and adolescents age, health communication/planning, self-efficacy, and self-determination support future research in executive functioning and HSM behavior in transitioning adolescents with ASD.

Depression in youth with ASD is a commonly co-occurring disorder that has been shown to compromise adaptive functioning and quality of life (Pezzimenti, Han, Vasa, & Gotham, 2019). Similar to a study of adolescents with diabetes by Verchota & Sawin (2016), this study did not find a significant relationship between reported depressive symptoms and HSM behavior. However, in this study depressive symptoms were moderately associated with health communication/planning, self-efficacy, and self-determination. According to parent report on the Background Information form, 22.5% of adolescent participants in this study were identified as having co-occurring depression. However, results of the depressive symptom measure in this study suggest that 35% of adolescents and 45% of parents indicate a moderate to severe level of adolescent depressive symptoms. This discrepancy suggests a possible under-treatment of depression in the sample. Considering the association between depression and heightened physical (gastrointestinal problems, seizure) comorbidities (Pezzimenti, Han, Vasa, & Gotham, 2019), the presence of depressive symptoms is an important assessment finding, despite the non-significant relationship to HSM behavior. In a review of the literature by Hudson, Hall, & Harkness (2019), significantly elevated lifetime rates of depression in individuals with ASD were associated with self-report over caregiver report. This finding is concerning since individuals with ASD are 4-times more likely than the general public to experience depression in their lifetime (Hudson, Hall, & Harkness, 2019). Consequently, adolescents with ASD and their parents should be made aware of resources they can access to address depression concerns, and future research exploring why they are unaware or not seeking treatment in this area is necessary.

Significant relationships between HSM behavior and many process domain variables further support careful assessment of health knowledge, health communication/planning, self-efficacy, and self-determination in health transition for adolescents with ASD. According to the moderate associations between process variables and HSM behavior found in this study, assessment is equally important for both adolescents and parents taking part in the health transition process as suggested by the American Academy of Pediatric guidelines (Reed-Knight, Blount, & Gilleland, 2014; White, et al., 2018). Furthermore, the process domain relationships found in this study are consistent with The Individual and Family Self-Management Theory that states that enhancement in health knowledge and beliefs may enhance self-regulation that leads to engagement in self-management behavior (Ryan & Sawin, 2009).

According to Bandura (1997), self-efficacy theory proposes that one's confidence in their ability to achieve a specific behavior determines the behaviors in which one will engage, how long one will engage, and to what extent one will engage. In relation to this study, this would mean that the higher confidence in the adolescents' ability to transition to more independent HSM, the more likely both are to achieve transition of HSM behavior. However, a negative relationship between the adolescent self-efficacy score and their rating of their HSM in the current study is perplexing. This anomaly may relate to the use of a general self-efficacy measure versus a self-efficacy measure specific to self-regulation. The General Self-Efficacy Scale used in this study is often used in studies to assess perceived self-efficacy associated with adaptation abilities and coping pertaining to stressful events and daily activities. There are four major sources of self-

efficacy identified by Bandura: social modeling, social persuasion, mastery experiences and psychological responses (Bandura, 1997; Bandura, Caprara, Barbaranelli, Gerbino, & Patorelli, 2003). While perceived self-efficacy plays a vital role in the process of self-management, perhaps a measure to assess beliefs of personal self-efficacy known to influence self-regulative standards, resiliency, and motivation would have been more appropriate for adolescents in this study. In the only known study to explore health self-efficacy in parents and adolescents with ASD, a common theme was low self-efficacy among adolescent and parent participants while youth were seeking health care independence (Cheak-Zamora, Teti, Maurer-Batjer, & Koegler, 2017). The researchers in that qualitative study discussed equal concern about caregiver confidence regarding their child's ability to manage health care independence. Parents low confidence as voiced in the Cheak-Zamora (2017) study, resulted in their reluctance to transition their child to more health responsibility. The moderate positive relationship between parents' ratings of their child's self-efficacy and HSM behavior, along with association with several other contextual and process variables in this dissertation study may suggest future research regarding self-efficacy's role in health transition of adolescents with ASD is needed.

Self-determination was found to have association with contextual and other process variables, as well as HSM behavior. Self-determination theory is a well-established concept supporting human motivation and psychological development and well-being (Deci & Ryan, 2008). For adolescents with ASD, self-determination skills may enhance problem-solving, decision making, goal setting, and self-monitoring ability. Autism research indicates that due to aspects of known ASD characteristics and co-

occurring conditions (social limitations, executive function deficits, adaptive behavior ability) that may limit opportunity to develop self-determination ability, this necessary life skill has been hindered in many individuals with ASD. As a result, youth with ASD have the lowest levels of self-determination and independence of all young adults (Chou Y.-C. , Wehmeyer, Palmer, & Lee, 2017). This contributes to further dependence on caregivers and U.S. government aid estimated at nearly $196 billion annually (Buescher, Cidav, Knapp, & Mandell, 2014; Leigh & Du, 2015). The self-determination relationship findings in this study are consistent with previous research relating self-determination to health knowledge, attitudes about health transition, and self-efficacy (Dwyer-Matzky, Blatt, Asselin, & Wood, 2017; Fishman, Barendse, Hait, Burdick, & Arnold, 2010). In an article aimed at health providers facilitating health transition in adolescents with developmental disabilities, Betz (2007) emphasized the need to promote self-determination skills early in life to improve transition outcomes. The role of self-determination in health transition is just as vital today and yet still missing from the process (Tesfaye, et al., 2019). The self-determination findings of this study, including associations with parent marital status, depressive symptoms, health communication/planning and self-efficacy, along with existing literature further support promotion of self-determination in health transition for adolescents with ASD to provide understanding of the adolescent's motivation and opportunity to gain necessary self-management skills and abilities.

Adolescent and parent report was mostly in agreement regarding moderately significant relationships between HSM behavior with health knowledge, health

communication/planning, and self-efficacy. Given this is the first known study to explore these variables in relation to HSM behavior in adolescents with ASD and their parent, the pattern of agreement in these relationships between adolescents and parents suggests adolescents with ASD were as able as parents to report and rate their experiences.

An exploratory hierarchical linear regression was conducted to evaluate the prediction of HSM behavior from contextual variables (adolescent age at ASD diagnosis, parent marital status, family income, executive function deficits, ASD complexity) and process variables (health knowledge, health communication/planning, self-efficacy, self-determination). In the final model, contextual variables (adolescent age of diagnosis with ASD, executive function, parents' marital status) followed by process variables (adolescent's knowledge and self-efficacy) together explained 43% of the variance in adolescent HSM behavior in this sample, which means 57% cannot be explained by these five predictor variables alone. Parents being married was the strongest predictor variable for adolescent HSM behavior. On average, parents not being married resulted in a 7.04 unit decrease in adolescent HSM behavior. Given that parents' marital status and family income had similar moderate correlations with HSM behavior, this finding, while purely speculative, may relate to socioeconomic factors that increase access to quality health care and insurance known to improve health outcomes (Karpur, Lello, Frazier, Dixon, & Shih, 2018).

Comparing Variable Perspective

Adolescents and parents both completed six comparable instruments that measured the adolescents' depressive symptoms, health knowledge, health

communication/planning, self-efficacy, self-determination, and HSM behavior. When comparing parent and adolescent report, two process measures were found to have significantly different average ratings: self-efficacy and self-determination.

Adolescents in this study rated their self-efficacy significantly higher than parents. This study finding is consistent with previous research suggesting parents of adolescents with ASD often lack confidence in their child's interpersonal skills (Locke & Mitchell, 2016). The parents in that study also accurately predicted that their child would express more confidence than they (parents) did. According to the literature, many parents of adolescents with ASD receive little, if any, formal training in health transition (Cheak-Zamora, Yang, Farmer, & Clark, 2013). Given the vast amount of responsibility parents carry in managing their child's health needs, building confidence in their child's abilities without support may be difficult. Findings of research with other youth with special health care needs suggest parent's low self-efficacy in their child's and their own abilities, may keep adolescents from having the opportunity to gain necessary transition skills and abilities (Fishman, Barendse, Hait, Burdick, & Arnold, 2010; Sawin, Bellin, Roux, Buran, & Brei, 2009). Previous research has underscored the need for guided transition services where parents are supported in the transition process and adolescents assume planned incremental responsibility for health self-management (American Academy of Pediatrics, 2011; Carbone, Behl, Azor, & Murphy, 2010; White, et al., 2018).

An example of a successfully implemented program using this approach follows a longitudinal study of transitioning adolescents undergoing long-term warfarin

management. Lasting health benefits resulted when both parent and adolescent patient entered the transition program together. As adolescents in the program gained confidence in their skills and abilities over time, parents also gained confidence in their child's skills and abilities and parents were safely phased out of the program (Bauman, Kuhle, Bruce, Bolster, & Massicotte, 2016). Furthermore, transition services like the one in that program were founded in the medical-home model and have been shown to decrease unmet health care needs (Farmer, et al., 2014). Considering the diversity within the autism spectrum, health autonomy may not always equate to total independence but instead may mean ongoing guidance and support to the youths' utmost ability. However, given differences in adolescent with ASD and parent priorities in other transition processes to adulthood (academic, occupational, etc.), early adolescent engagement in the transition process is key to optimizing self-management behavior (Hume, et al., 2017; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012). In the study by Locke & Mitchell (2016), the authors suggest that building on the suspected overconfidence of adolescents with ASD may protect them from feelings of discouragement, which was much like neurotypical transitioning adolescents in that study.

If self-efficacy is about participants' confidence for engaging in HSM behavior, then self-determination reflects the adolescents' motivation and opportunity to engage in HSM behavior. When comparing parent and adolescent rating of adolescent self-determination, adolescents in this study rated themselves significantly higher than parents rated them in this area. This is the first known study to compare adolescent with ASD and parent report of the adolescents' self-determination in relation to health transition.

Research examining self-determination in youth with ASD has recently began to appear in the literature but strictly has come from the parent perspective or far less often, only the youth perspective (Cheak-Zamora, Maurer-Batjer, Malow, & Coleman, 2020; Chou Y.-C. , Wehmeyer, Palmer, & Lee, 2017). This nascent research has focused on specific relationships with self-determination (quality of life, specific measurement use, or cognitive ability) instead of its association with aspects of health transition. Therefore, comparative analysis of this study to previous studies from both parent and adolescent perspective is very limited. Other research in this area suggests that higher rates of self-determination have been linked to positive outcomes such as quality of life, social inclusion, better employment, and independent living for youth with ASD transitioning in areas other than health. For instance, in a study involving high-school students with ASD taking part in adult transition planning, students with higher self-advocacy, who spent more time in general education, and who regularly discussed post high-school plans were more active participants in the process (Griffin, Taylor, Urbano, & Hodapp, 2014).

Social Facilitation in Transition

The final aim of this study was to examine social facilitation, defined as what parents are doing to enhance their child's HSM behavior and what the adolescent is doing to learn how to manage their health. Findings of this study suggest that some transition of health management from the parent to their adolescent child is occurring despite the absence of formal transition programs. Moreover, the level of reported motivation and active participation by adolescents in the HSM process is encouraging, especially considering that half the adolescents were in the 12 -14-year age group. Over half of

adolescent participants and close to three-quarters of parents agreed that parents were teaching their child about their medications and how to talk to their doctor. Given that health knowledge was a moderately strong predictor of HSM behavior, these are important aspects for adolescents to learn. Adolescents also seemed to be learning how to monitor for and prevent illness. Unfortunately, it appears that some aspects of health transition are not being taught due to lack of resources, support, or awareness that health transition is a vital part of the adolescent's future well-being. Larger gaps in what adolescents are doing appear around independently managing their health. Tasks such as using adaptive devices, scheduling doctor/therapy appointments, and completing a treatment regimen were reported less frequently. In the only other known study to examine health transition from parent and adolescent with ASD perspective, independent engagement in health components for adolescents was found to be "challenging" (Cheak-Zamora, Teti, Maurer-Batjer, & Koegler, 2017). But, similar to findings in this study, while many parents managed most aspects of their child's health small steps toward independence were being made.

Gaps in what parents are teaching, what adolescents are doing, and significant differences in parent and adolescent perspective reinforces the need for guidance from health professionals as adolescents move toward more independent HSM. Parents report many barriers to teaching their child HSM behavior. Competing family priorities was the most reported barrier by parents (43%). For parents of children with ASD, perceived family burden has been most often associated with lower treatment adherence in previous

studies (Hock, Kinsman, & Ortaglia, 2015). Therefore, what parents teach, and if parents teach HSM behavior, may be influenced by the perceived impact it has on the family.

Adolescent perspective is key to understanding their engagement in HSM behavior. Findings of discrepancies between parent and adolescent perspectives on the child's HSM behaviors underscore the importance of hearing directly from adolescents about their understanding of their HSM behaviors. There also appears to be some discrepancy between the high level of endorsement by adolescents on items in the readiness scale about HSM behavior in comparison to mean scores on adolescent health communication/planning and $Star_x$ HSM behavior scale. This discrepancy appears again in what adolescents state they are doing on their own during social facilitation. Social facilitation between adolescent and parent during health transition is an area of study that warrants further research given the lack of formal transition services currently available. This is especially true given current literature suggesting parent and youth priorities and perspectives during the transition process do not always align (Locke & Mitchell, 2016; Rehm, Fuentes-Afflick, Fisher, & Chesla, 2012).

LIMITATIONS

The findings of this study must be considered in the context of key limitations in the methodology that reduce the generalizability of these findings. First, future research in this area would benefit from a larger sample size allowing for higher level analysis. Unfortunately, Covid-19 restrictions interfered with recruitment efforts, resulting in a smaller sample than initially anticipated. A larger sample may have allowed expansion of complex multivariate analyses, especially around path analysis given the many

interrelationships found in this study. With 57% of HSM behavior variance in this study unexplained, a better understanding of association between variables would be helpful for stakeholders engaging in health transition in prioritizing areas of focus. Moreover, a larger sample size may have further strengthened study findings. Second, all data about HSM behaviors were self-reported, objective measures such as health outcomes should be included in future HSM research. Third, despite clearly stated guidelines, online survey research does not guarantee that solicited responses were obtained independently or from the intended participant. An email address for adolescents was requested from parents to provide information and study links directly to the adolescent participant. However, this was not required nor always feasible given the age and diagnosis of some adolescent participants. Fourth, while recruitment efforts were limited to agencies, organizations, and providers serving individuals with ASD, diagnosis of ASD was established by parent report only. However, studies suggest a high rate of concordance between parent report of ASD diagnosis and clinical verification in research (Daniels, et al., 2012; Warnell, et al., 2015). Given the extent of fraudulent interest in participation experienced at three different periods during the study, there is no way to ascertain the accuracy of diagnosis resulting from parent-report. Finally, because this was an exploratory study, the Type 1 error level for each individual analysis was not modified to protect against experiment wide error. There are two additional areas of direct concern and addressed in greater detail in the following paragraphs.

Instrumentation

Scores for two adolescent instruments, both subscales for the $Star_x$, lacked general acceptable reliability: health knowledge and HSM behavior (alphas = .69 and .65, respectively). The lower alpha coefficient for the only dependent variable being measured was not ideal. Given the lack of adequate instruments designed for youth with ASD, adaption to existing scales for youth with special health care needs was necessary. Shortcomings of these measures included assumptions that transitioning youth were attending school (AIR Self-Determination) or taking medications ($Star_x$), which required further adaptation. For instance, in not reporting the opportunities at school subscale of the AIR instrument two important pieces of information may have been lost. One, report of opportunity for self-determination in another setting may have improved our understanding of self-determination in the ASD population and two, additional parent and adolescent report might have provided added diversity in participant perspective. This study highlights the need for measures designed for the diversity seen in the ASD population and occurring in the process of health transition. Despite the instrument limitations mentioned, two promising measures for future research may have been found. The PROMIS Emotional Distress Depression short form and AIR Self-Determination scales both yielded good internal consistency reliability for parent and adolescent measures.

A limitation to this study in addressing social facilitation between parents and adolescents with ASD exists around condition specific questions that should be added relating to the adolescents perceived deficits impacting their ability to engage in HSM

behavior. Free-text responses from parents in this study identified communication deficits as a barrier for their child in completing certain HSM behaviors. Given communication challenges are within the triad of diagnostic criteria for ASD according to the Diagnostic and Statistical Manual of Mental Disorders, fifth edition (DSM–5), varying degree of communication difference is expected. However, assessing for how communication, social interaction, and behavioral differences impact self-management behaviors (talking to the doctor, making appointments, managing adaptive devices, etc.), may provide additional guidance on where to prioritize areas of support during the transition process. Therefore, the addition of one or two condition specific questions (e.g. What barriers relating to your child's ASD keep them from engaging is HSM behavior?) is merited.

Sample

The convenience sampling strategy may have created selection bias. This study sample was relatively homogenous; mostly White, middle-class, two-parent families living in one large southwestern state. Recruiting efforts became limited once the pandemic spread through Texas and the opportunity to reach diverse populations became dependent on parent engagement in support groups across the state. Therefore, it is unlikely that parents or adolescents not actively engaged in an autism clinic or autism support systems were notified about the study. Racial and ethnic diversity limitations in research restrict representation and understanding of the autism spectrum. While future studies will make efforts to recruit a more diverse sample (flyer and study in Spanish, targeted presentations for minority support groups, etc.), a more diverse sample may not have been possible due to greater system barriers. The CDC (2018) reports that ASD

occurs in all racial, ethnic, gender, and socioeconomic groups. Numerous studies exploring health disparities within the ASD population have found these same variables to be barriers to timely diagnosis and treatment for autism (Bishop-Fitzpatrick & Kind, 2017; Karpur, Lello, Frazier, Dixon, & Shih, 2018; Magaña, Parish, Rose, Timberlake, & Swaine, 2012; Magaña, Parish, & Son, 2015). According to the Centers for Disease Control and Prevention (CDC), White children are 1.1 times more likely than Black children and 1.2 times more likely than Hispanic children to receive an ASD diagnosis (Centers for Disease Control and Prevention, 2018). Recent data indicate that smaller differences between racial and ethnic groups exist when compared to previous years; however, consistently higher patterns of ASD prevalence among residents of neighborhoods with a higher socioeconomic status continues (Centers for Disease Control and Prevention, 2018). Some studies suggest that cultural sensitivity and competence training are key for health care providers in addressing this ongoing gap in diagnosis and treatment (Magaña, Parish, & Son, 2015). Underrepresentation of Black and Latino individuals with ASD in research further complicates our understanding of ASD and may lead to ethnic and racial health disparities (Magaña, Parish, & Son, 2015).

Females having ASD may also be underrepresented in this sample. While the CDC (2020) reports ASD is four times more common among boys than girls, recent studies indicate that existing diagnostic criteria and screening instruments may be biased in gender representation of ASD (Haney, 2016). Early autism research highlighting both males and females with fewer autistic challenges (identified as Asperger syndrome) suggest a smaller male-to-female ratio then currently identified by the CDC (Haney,

2016). The current skew towards males versus females with ASD could relate to a limited understanding of ASD that focuses on presentation of social autistic traits and behavioral representation of males only (Haney, 2016; Mandy, Pellicano, St Pourcain, Skuse, & Heron, 2018). For instance, males may outwardly display problems through aggressive behaviors more widely recognized by the DSM-5 and other diagnostic criteria as opposed to the internalized psychic behaviors presenting as anxiety, mood, or eating problems often exhibited by females (Thompson, Caruso, & Ellerbeck, 2003). More research is needed to investigate gender bias in our understanding and diagnosis of ASD.

Finally, given that parents and adolescents look to health care providers for guidance during the health transition process, a limitation of this study is the missing provider perspective. Identifying what barriers and facilitators providers encounter when guiding youth with ASD would provide valuable insight and is worthy of future study.

Despite these limitations, the study has important strengths. First person perspective from individuals with ASD is a known gap in the science (Tesfaye, et al., 2019). Parents, teachers, and providers regularly represent our understanding of ASD. This study took strides to represent the voice of adolescent participants in capturing their perspective in the health transition process. The study findings of discrepancies between parents' and adolescents' perspectives on adolescent HSM behaviors and associated process variables validates the decision to enable adolescents to give their own responses, rather than allowing proxy responses from parents. Nevertheless, this decision may have excluded adolescents who were not able to complete the study measures independently. Often underrepresented, female adolescent participants were included, although they

represented less than one quarter of this study sample. Additionally, this study encouraged a true representation of the autism spectrum and did not differentiate between individual abilities or disabilities, although it is recognized that lower functioning adolescents with ASD were eliminated if they were unable to complete the online data collection. Extra support was offered when individuals felt they could not complete the survey independently. Approximately 33% of individuals with ASD have a co-occurring IDD diagnosis (Maenner, et al., 2016). While only five adolescent participants (13%) in this study identified as having IDD, autism research often is represented by individuals on either end of the spectrum. The goal of this study was to provide a representation of the autism spectrum as a whole.

IMPLICATIONS

Findings from the current study show that contextual and process domain variables are associated with HSM behavior in adolescents with ASD even when formal health transition services may be absent. However, the quality, content, and/or extent of transition is not assured in the absence of guided support.

Practice/Teaching

Transition programs are designed to assist youth in taking ownership of their illness and fill the gap between increased responsibility and the absent skills, knowledge, and motivation necessary to manage one's health throughout their lifetime (White, et al., 2018). While the American Academy of Pediatrics provided guidelines for goals and timelines for transitioning youth, implementation of these programs has been limited due to the lack of conceptual frameworks informing the how and what aspect of transition

(Betz, et al., 2014; Schwartz, Tuchman, Hobbie, & Ginsberg, 2011). The AHSM model used to guide this study is informed by guidelines developed by the American Academy of Pediatrics for health transition and provides promising practice, research, and policy implications. These frameworks assist in the development of interventions and resources providers use in clinical practice. Evidenced based practice relies on these frameworks in practice and research, which then may become implemented into curriculum being taught to future health providers. Findings from this study provide the first steps in testing the parameters of the AHSM model. Further application and future research incorporating the model is warranted.

Incorporating aspects of health transition into existing behavioral therapy and training may be a way of supporting these families. Several parents reported the use of applied behavioral therapy in their child's treatment. Applied behavioral therapy and cognitive behavioral therapy are evidenced-based treatments associated with long-term behavior change (Ung, Selles, Small, & Storch, 2015; van Steensel & Bögels, 2015; Wong, et al., 2015). These therapies have been very effective in supporting transition to independent functioning in areas such as occupation, but have not been used in the area of health. Collaborating with behavior therapist and incorporating health transition into already provided services may be a productive way to enhance HSM behavior.

Additionally, public schools provide special education and related services at no cost to parents for youth aged 3 through 21 years. Developed under the Individuals with Disabilities Education Act, special education gives children with ASD the right to receive special services and assistance, not only in school but at home, in hospitals or institutions,

or in other settings as established by an Individualized Education Program (IEP). Individual needs and certain transitional services provide preparation for life after high school and are written into the IEP based on an individual's support team. The IEP can include addressing communication challenges, executive functioning deficits, occupational therapy, etc. However, health transition services are often left to the health care provider and not incorporated into the individual's IEP. School nurses bridge the gap between healthcare and education (Johnson K. , 2017). School nurses address a variety of student health needs that include physical, mental, emotional, and social health. If school nurses were to partner with special education services, educational institutions can easily support many of the health transition gaps currently facing adolescents with ASD and their family.

Research

This study reveals gaps in current health transition literature for youth with ASD. Most previous studies have focused on other youth with other special health care needs or did not well define participants with ASD in their sample description. A clear need for transition research is to explicate sample description when the study includes youth having diverse health care conditions. This is especially true for studies using preexisting survey data of youth with special health care needs or youth with developmental disabilities. The lack of studies in the literature identifying adolescents with ASD in health transition reflects this need. This gap in the literature may also be attributed to adolescents with ASD simply being absent from transition research, which makes this

study a substantial contribution to the science and understanding of health transition for youth with ASD.

Future research may benefit from the identified variables, relationships, and framework provided by this study, especially with the modifiable variables found in the process domain. Results of the hierarchical analysis presented in this study suggest that process variables, such as health knowledge, can increase the likelihood that adolescents will report engaging in HSM behaviors, even after controlling for contextual variables that may be less modifiable. While social facilitation was a limited aspect of this study, few studies have provided adolescent and parent perspectives regarding current HSM behavior practices. For parents, health transition for their children is also a time of transition for parents. Parents voiced facing uncertainty and limitations in information and support as barriers to transitioning their child. A qualitative study examining parent perspective of their child's transition may provide better understanding of the parent's transition and support needs during the process. Such studies should seek to include parents and adolescents from communities of color, so that their experiences are reflected as well as those of white parents. The possible influence of other variables, such as peer support, on HSM behaviors should be explored as well.

This study provided valuable first-person perspective from adolescents with ASD, which is missing from the literature. Research scientists must find a way to incorporate the voice of individuals with ASD into their research. While caregiver and provider perspective may be helpful, only an individual with ASD can speak to their experience of having ASD.

Policy

There are several potential policy implications from this study. The first is to encourage and fund more family-centered transition programs where caregivers and youth can collaborate with providers to build HSM capabilities. Health care providers have consistently voiced the need for improved services for individuals with ASD, but cite lack of transition training, resources, collaboration, and time as barriers to providing necessary support (Kuhithau, Warfield, Hurson, Delahaye, & Crossman, 2014; Warfield, 2015). Policy change supporting health care professionals in acquiring the necessary training in planned transition and supplementary time necessary to properly support these high-risk individuals and families is crucial. Qualified health care providers are a key component of the family – adolescent - provider triad and without the necessary training and resources they need to fulfill their role properly, there will continue to be a gap in health outcomes impacting these families. Although this study was not designed to explore the influence of health care providers on adolescents' HSM behaviors, their key role, as well as the impact of the systems in which they provide care, should be investigated in future research.

Other policy implications include addressing health transition in existing special education programs that can be written into the student's IEP. Providing communication and executive functioning support targeting future health reinforces success in other transition areas already addressed by these services. In addition, working with parents and other providers often attending annual IEP meetings may further support a team approach, instead of services that are often siloed, which could further relieve parents

from playing the case manager role to which they are not trained. Additionally, the IEP team can work in conjunction with the school nurse to provide vital guidance. School nurses bridge the gap between health and education by addressing the students physical, mental, social, and emotional health needs. Unfortunately, Texas law does not require public schools to have a full-time school nurse on staff. The recent pandemic has highlighted a gross underrepresentation of public-school nurses in the state (Oberg & Rafique, 2020). Policy promoting the need for public school nurses to support health transition may need to start with implementing policy providing a full-time nurse on each school campus.

CONCLUSIONS

The American Academy of Pediatrics has presented guidelines for providers within the medical home model to promote health autonomy and improve health outcomes for adolescents as they transition to more health responsibility. Unfortunately, the lack of conceptual models and frameworks guiding providers in implementing these guidelines has contributed to a lack of transition programs and services. As a result, many parents carry the responsibility of transitioning their adolescent children. Adolescents with ASD are at a two times greater risk of unmet health care needs when compared to other youth with special health care needs that may lead to premature mortality. Yet few of these adolescents receive formal transition services. Furthermore, little is known about health transition for adolescents with ASD. This correlational descriptive study aimed to identify factors associated with HSM behavior in adolescent with ASD. The AHSM model devised from the literature and used to guide identification of potential contextual

and process variables of interest in this study provides promising potential. Many relationships were well explained by the model.

Although adolescents with ASD may not be receiving formal transition services, many in this study are receiving some form of transitional support from parents. However, findings from this study identified gaps (making health appointments, using adaptive devices, completing a treatment regimen) in what parents are teaching their children and what adolescents are doing to self-manage their health in the wake of limited guidance and support. Differences in perspective between adolescents and parents further reinforce the need for family-centered and coordinated health transition guidance.

Appendices

APPENDIX A - **PROMIS DEPRESSIVE SYMPTOM SCALE (ADOLESCENT VERSION)**

Participant ID: _____

Instructions to the child: The questions below ask about feelings of sadness, being down, or hopelessness and how often you may be bothered by these feelings **during the past 7 days**. Please respond to each item by checking the box that best describes how you feel.

In the past SEVEN (7) Days…	Never	Almost Never	Sometimes	Often	Almost Always	Item Score
1. I could not stop feeling sad.						
2. I felt alone.						
3. I felt everything in my life went wrong.						
4. I felt like I couldn't do anything right.						
5. I felt lonely.						
6. I felt sad.						
7. I felt unhappy.						
8. I thought that my life was bad.						
9. Being sad made it hard for me to do things with my friends.						
10. I didn't care about anything.						
11. I felt stressed.						
12. I felt too sad to eat.						
13. I wanted to be by myself.						
14. It was hard for me to have fun.						
					Total Score: _____	

Scoring of PROMIS (adolescent version)

Each item on the measure is rated on a 5-point scale (1=never, 2=almost never, 3=sometimes, 4=often, and 5=almost always). Total score ranges from 14 to 70 with higher scores indicating greater severity of depressive symptoms.

PROMIS Depressive Symptom Scale (Parent Version)

Participant ID: _____

Instructions to the parent: The questions below ask about your perception of your child feelings of sadness, being down, or hopelessness and how often your child has been bothered by these feelings **during the past 7 days**. Please respond to each item by checking the box that best describes your child.

In the past SEVEN (7) Days, my child said he/she…	Never	Almost Never	Sometimes	Often	Almost Always	Item Score
1. Could not stop feeling sad.						
2. Felt alone.						
3. Felt like he/she couldn't do anything right.						
4. Felt lonely.						
5. Felt sad.						
6. Felt unhappy.						
7. Thought that his/her life was bad.						
8. Didn't care about anything.						
9. Felt stressed.						
10. Felt too sad to eat.						
11. Wanted to be by himself/herself.						
					Total Score: _____	

Scoring of PROMIS (parent version)

Each item on the measure is rated on a 5-point scale (1=never, 2=almost never, 3=sometimes, 4=often, and 5=almost always). Total score ranges from 11 to 55 with higher scores indicating greater severity of depressive symptoms.

APPENDIX B - STAR$_X$ TRANSITION READINESS QUESTIONNAIRE (ADOLESCENT VERSION)

Participant ID: _____

Adolescents with chronic health conditions need to have special skills and do special tasks to stay healthy. On the following pages, please check the box underneath the answers that describe you most. If you do not understand a question, just ask for help. We are here to help you.

Self-Management Behavior:

- How often have you done the following?
- Please check the box that tells how often you have done each thing in the PAST 3 MONTHS.

In the PAST 3 MONTHS…	Never	Almost Never	Sometimes	Almost Always	Always	I do not take medicines right now
1. How often did you make an effort to understand what your doctor told you?						
2. How often did you take your medicines on your own?						
3. How often did you ask your doctor or nurse questions about your illness, medicines or medical care?						
4. How often did you make your own appointments?						
5. How often did you need someone to remind you to take your medicines?						
6. How often did you use things like pillboxes, schedules, or alarm clocks or help you take your medicines when you were supposed to?						

7. How often did you use the internet, books, or other guides to find out more about your illness?						
8. How often did you forget to take your medicines?						
9. How often did you work with your doctor to take care of new health problems that came up?						

Self-Management Knowledge:

- Some adolescents know a lot about their health and some adolescents don't.
- How much do you know?
- Please check the answer that best describes how much you feel you know TODAY.

How much you feel you know TODAY…	Nothing	Not Much	A little	Some	A lot	I do not take medicines right now
1. How much do you know about your illness?						
2. How much do you know about taking care of your illness?						
3. How much do you know about what will happen if you don't take you medicines?						

Self-Management Communication & Planning:

- Some adolescents may find it hard to do certain things.
- How easy or hard is it for you to do the following things?
- Please check the answer that best describes how you feel TODAY.

How you feel TODAY…	Very Hard	Somewhat Hard	Neither Hard nor Easy	Somewhat Easy	Very Easy	I do not take

						medicines right now
1. How easy or hard is it to talk to your doctor?						
2. How easy or hard is it to make a plan with your doctor to care or your health?						
3. How easy or hard is it to see your doctor by yourself?						
4. How easy or hard is it to take your medicines like you are supposed to?						
5. How easy or hard is it to take care of yourself?						
6. How easy or hard do you think it will be to move from pediatric to adult care?						

Question #	**Score = 0**	**Score = 1**	**Score = 2**	**Score = 3**	**Score = 4**	**Score = 5**	**Score = 6**
1	I do not take medicines right now	Never	Almost Never	Sometimes	Almost Always	Always	
2		Never	Almost Never	Sometimes	Almost Always	Always	I do not take medicines right now
3	I do not take	Never	Almost Never	Sometimes	Almost Always	Always	

	medicines right now						
4	I do not take medicines right now	Never	Almost Never	Sometimes	Almost Always	Always	
5		Always	Almost Always	Sometimes	Almost Never	Never	I do not take medicines right now
6		Never	Almost Never	Sometimes	Almost Always	Always	I do not take medicines right now
7	I do not take medicines right now	Never	Almost Never	Sometimes	Almost Always	Always	
8		Always	Almost Always	Sometimes	Almost Never	Never	I do not take medicines right now
9	I do not take medicines right now	Never	Almost Never	Sometimes	Almost Always	Always	

10	I do not take medicines right now	Nothing	Not Much	A Little	Some	A lot	
11	I do not take medicines right now	Nothing	Not Much	A Little	Some	A lot	
12		Nothing	Not Much	A Little	Some	A lot	I do not take medicines right now
13	I do not take medicines right now	Very Hard	Somewhat Hard	Neither Hard nor easy	Somewhat Easy	Very Easy	
14	I do not take medicines right now	Very Hard	Somewhat Hard	Neither Hard nor easy	Somewhat Easy	Very Easy	
15	I do not take medicines right now	Very Hard	Somewhat Hard	Neither Hard nor easy	Somewhat Easy	Very Easy	

16		Very Hard	Somewhat Hard	Neither Hard nor easy	Somewhat Easy	Very Easy	I do not take medicines right now
17	I do not take medicines right now	Very Hard	Somewhat Hard	Neither Hard nor easy	Somewhat Easy	Very Easy	
18	I do not take medicines right now	Very Hard	Somewhat Hard	Neither Hard nor easy	Somewhat Easy	Very Easy	

STAR$_x$ Transition Readiness Questionnaire (Parent Version)

Participant ID: _____

Self-Management Behavior:

- How often has your child done the following things?
- Please check the box that shows how often your child has done each thing in the PAST 3 MONTHS.

In the PAST 3 MONTHS…	Never	Almost Never	Sometimes	Almost Always	Always	I do not take medicines right now
1. How often did your child make an effort to understand what his/her doctor told them?						
2. How often did your child take his/her medicines on their own?						
3. How often did your child ask his/her doctor or nurse questions about their illness, medicines or medical care?						
4. How often did your child make their own appointments?						
5. How often did your child need someone to remind him/her to take their medicines?						
6. How often did your child use things like pillboxes, schedules, or alarm clocks or help him/her take their medicines when they were supposed to?						
7. How often did your child use the internet, books, or other guides to find out more about his/her illness?						

8. How often did your child forget to take his/her medicines?						
9. How often did your child work with his/her doctor to take care of new health problems that came up?						

Self-Management Knowledge:

- Some adolescents know a lot about their health and some adolescents don't.
- How much does your child know?
- Please check the answer that best describes your child most.

	Nothing	Not Much	A little	Some	A lot	I do not take medicines right now
10. How much does your child know about his/her illness?						
11. How much does your child know about taking care of his/her illness?						
12. How much does your child know about what will happen if he/she doesn't take their medicines?						

Self-Management Communication & Planning:

- Some adolescents may find it hard to do certain things.
- How easy or hard is it for your child to do the following things?
- Please check the answer that best describes how easy or hard you feel this is/will be for your child.

	Very Hard	Somewhat Hard	Neither Hard nor Easy	Somewhat Easy	Very Easy	I do not take medicines right now
13. How easy or hard is it for your child to talk to his/her doctor?						
14. How easy or hard is it for your child to make a plan with his/her doctor to care or their health?						
15. How easy or hard is it for your child to see his/her doctor by themselves?						
16. How easy or hard is it for your child to take his/her medicines like they are supposed to?						
17. How easy or hard is it for your child to take care of himself/herself?						
18. How easy or hard do you think it will be for your child to move from pediatric to adult care?						

APPENDIX C - GENERAL SELF-EFFICACY (ADOLESCENT VERSION)

Participant ID: _____

Scoring General Self-Efficacy Scale

The total score is calculated by finding the sum of all items. The total score ranges between 10 and 40, with higher score indicating more self-efficacy.

	Not at all true	Hardly true	Moderately true	Exactly true
All questions	1	2	3	4

Instructions: Mark the box that best describes you.

	Not at all true	Hardly true	Moderately true	Exactly true
1. I can always manage to solve difficult problems if I try hard enough.				
2. If someone opposes me, I can find the means and ways to get what I want.				
3. It is easy for me to stick to my aims and accomplish my goals.				
4. I am confident that I could deal efficiently with unexpected events.				
5. Thanks to my resourcefulness, I know how to handle unforeseen situations.				
6. I can solve most problems if I invest the necessary effort.				
7. I can remain calm when facing difficulties because I can rely on my coping abilities.				
8. When I am confronted with a problem, I can usually find several solutions.				
9. If I am in trouble, I can usually think of a solution.				
10. I can usually handle whatever comes my way.				
				Total Score: _____

General Self-Efficacy (parent version)

Instructions: Mark the box that best describes your child.

	Not at all true	Hardly true	Moderately true	Exactly true
1. My child can always manage to solve difficult problems if he/she tries hard enough.				
2. If someone opposes my child, he/she can find the means and ways to get what he/she wants.				
3. It is easy for my child to stick to his/her aims and accomplish his/her goals.				
4. My child is confident that he/she can deal efficiently with unexpected events.				
5. Thanks to my child's resourcefulness, he/she know how to handle unforeseen situations.				
6. My child can solve most problems if he/she invest the necessary effort.				
7. My child can remain calm when facing difficulties because he/she can rely on his/her coping abilities.				
8. When my child is confronted with a problem, he/she can usually find several solutions.				
9. If my child is in trouble, he/she can usually think of a solution.				
10. My child can usually handle whatever comes his/her way.				
				Total Score: _____

APPENDIX D - AIR SELF-DETERMINATION SCALE (ADOLESCENT FORM)

Participant ID: _____

HOW TO FILL OUT THIS FORM

Please answer these questions about how you go about getting what you want or need. This may occur at school, or after school, or not at school and could be related to your friends, your family, or a job or hobby you have. THIS IS NOT A TEST and **there are no right or wrong answers**. The questions will help us learn about what you do well and where you may need help.

Goal: You may not be sure what some of the words in the questions mean. For example, the word goal is used a lot. **A goal is something you want to get or achieve**, either now or next week or in the distant future, like when you are an adult. You can have many different kinds of goals. You could have a goal that has to do with school (like getting a good grade on a test or graduating from high school or college). You could have a goal of saving money to buy something (a new video game or new cell phone) or doing better in a sport or hobby (playing a musical instrument or playing basketball). Each person's goals are different because each person has different things that they want or need or that they are good at or want to be good at.

Plan: Another word that is used in some of the questions is plan. **A plan is the way you decide to meet your goal, or the steps you need to take in order to get what you want or need.** Like goals, you can have many different kinds of plans. An example of a plan to meet the goal of playing a musical instrument would be: to find an instrument you enjoy playing, decide whether you are wanting to teach yourself how to play or get a musical instructor, learning how to read music, practicing and playing the instrument along with others, study masters of that instrument.

HOW TO MARK YOUR ANSWERS

EXAMPLE QUESTION: I check for errors after completing a project.

EXAMPLE ANSWER: Mark the number (only one) of the answer which tells what you are most like:

1. Never – I never check for errors

2. Almost Never – I almost never check for errors
3. Sometimes – I sometimes check for errors
4. Almost Always – I almost always check for errors
5. Always – I always check for errors

THINGS I DO

	Never	Almost Never	Sometimes	Almost Always	Always
1. I know what I need, what I like, and what I'm good at.					
2. I set goals to get what I want or need. I think about what I am good at when I do this.					
Things I Do – Total Items 1 + 2 = _____					
3. I figure out how to meet my goals. I make plans and decide what I should do.					
4. I begin working on my plans to meet my goals as soon as possible.					
Things I Do – Total Items 3 + 4 = _____					
5. I check how I'm doing when I'm working on my plan. If I need to, I ask others what they think of how I'm doing.					
6. If my plan doesn't work, I try another one to meet my goals.					
Things I Do – Total Items 5 + 6 = _____					

HOW I FEEL

	Never	Almost Never	Sometimes	Almost Always	Always

1. I feel good about what I like, what I want, and what I need to do.					
2. I believe that I can set goals to get what I want.					
Things I Do – Total Items 1 + 2 = _____					
3. I like to make plans to meet my goals.					
4. I like to begin working on my plans right away.					
Things I Do – Total Items 3 + 4 = _____					
5. I like to check on how well I'm doing in meeting my goals.					
6. I am willing to try another way if it helps me to meet my goals.					
Things I Do – Total Items 5 + 6 = _____					

<u>WHAT HAPPENS AT SCHOOL</u> (if applicable)

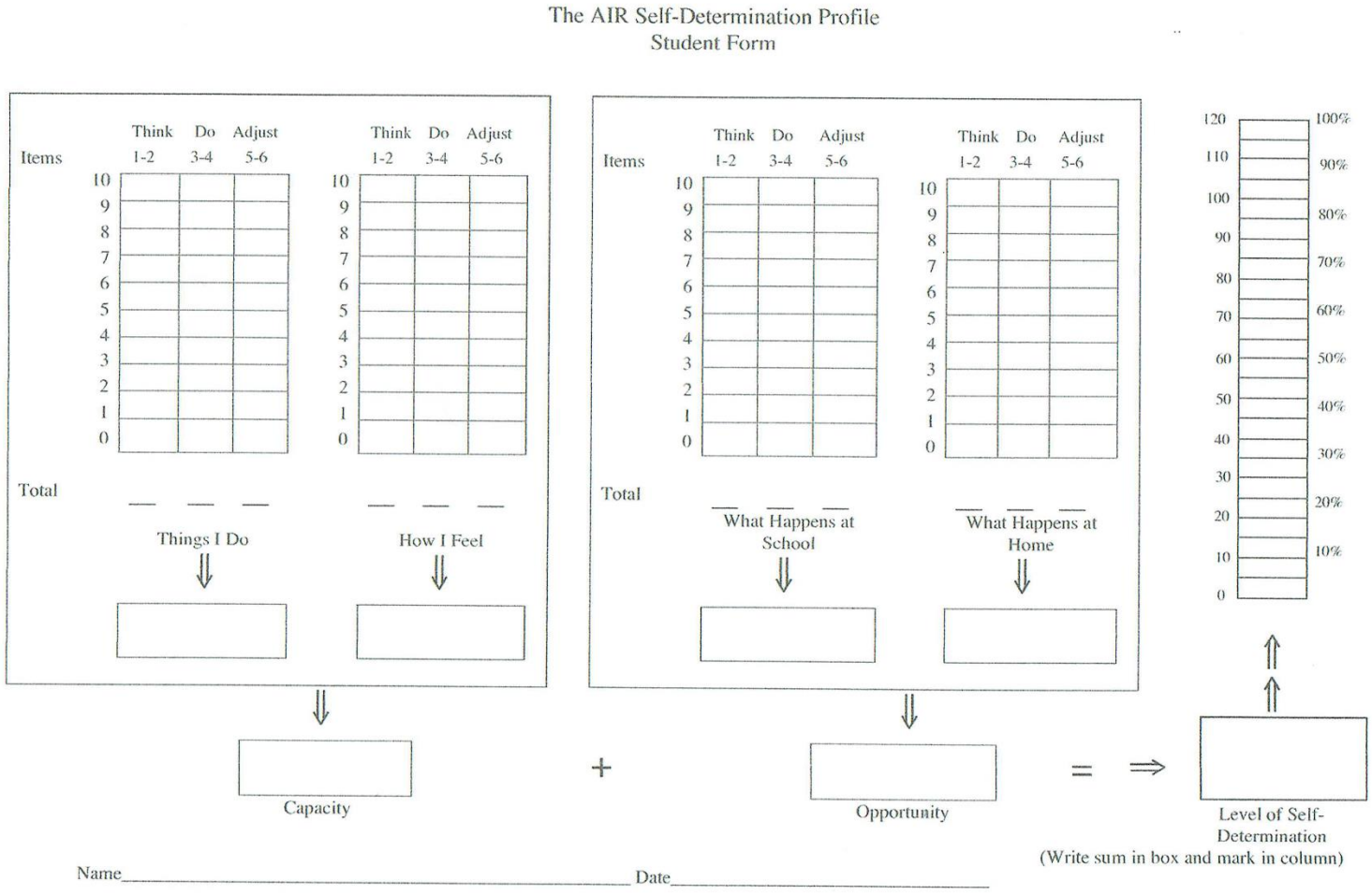
	Never	Almost Never	Sometimes	Almost Always	Always
1. People at school listen to me when I talk about what I want, what I need, or what I'm good at.					
2. People at school let me know that I can set my own goals to get what I want or need.					
Things I Do – Total Items 1 + 2 = _____					
3. At school, I have learned how to make plans to meet my goals and to feel good about them.					
4. People at school encourage me to start working on my plans right away.					
Things I Do – Total Items 3 + 4 = _____					

5. I have someone at school who can tell me if I am meeting my goals.					
6. People at school understand when I have to change my plan to meet my goal. They offer advice and encourage me when I'm doing this.					
					Things I Do – Total Items 5 + 6 = _____

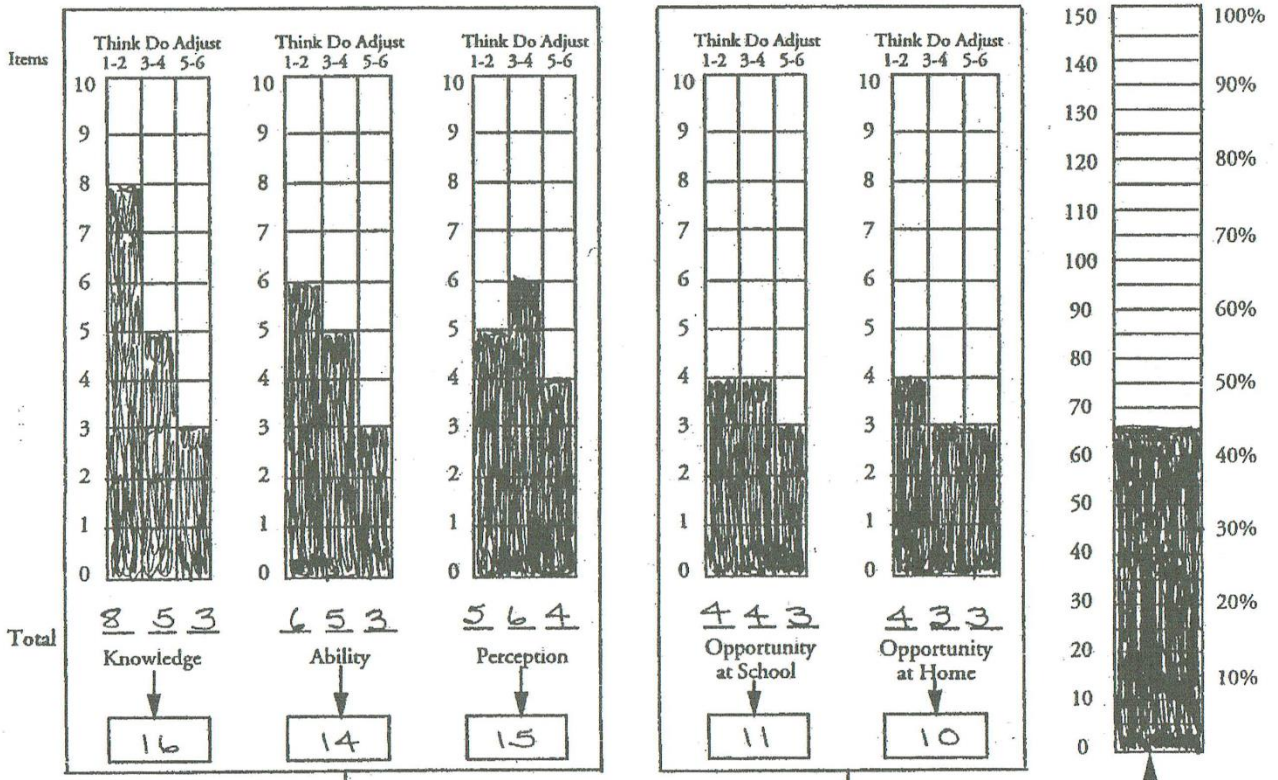
WHAT HAPPENS AT HOME

	Never	Almost Never	Sometimes	Almost Always	Always
1. People at home listen to me when I talk about what I want, what I need, or what I'm good at.					
2. People at home let me know that I can set my own goals to get what I want or need.					
					Things I Do – Total Items 1 + 2 = _____
3. At home, I have learned how to make plans to meet my goals and to feel good about them.					
4. People at home encourage me to start working on my plans right away.					
					Things I Do – Total Items 3 + 4 = _____
5. I have someone at home who can tell me if I am meeting my goals.					
6. People at home understand when I have to change my plan to meet my goal. They offer advice and encourage me when I'm doing this.					
					Things I Do – Total Items 5 + 6 = _____

Scoring Form and Example of Scoring AIR Self-Determination Scale



The AIR Self-Determination Profile
Educator Form



Student name Pat Reed

Date 1/19/95

AIR Self-Determination Scale (Parent Form)

Participant ID: _____

HOW TO MARK YOUR ANSWERS

EXAMPLE QUESTION: My child checks for errors after completing a project.

EXAMPLE ANSWER: Mark the number (only one) of the answer which tells what your child is most like:

1. Never – My child never checks for errors
2. Almost Never – My child almost never checks for errors
3. Sometimes – My child sometimes checks for errors
4. Almost Always – My child almost always checks for errors
5. Always – My child always checks for errors

THINGS I DO (Parent perception of what your child does)

	Never	Almost Never	Sometimes	Almost Always	Always
1. My child knows what he/she needs, what he/she likes, and what he/she is good at.					
2. My child sets goals to get what he/she wants or needs. My child thinks about what he/she is good at when he/she does this.					
Things I Do – Total Items 1 + 2 = _____					
3. My child figures out how to meet his/her goals. My child makes plans and decides what he/she should do.					

4. My child begins working on his/her plans to meet his/her goals as soon as possible.					
					Things I Do – Total Items 3 + 4 = _____
5. My child checks how he/she is doing when working on his/her plan. If he/she need to, he/she asks others what they think of how he/she is doing.					
6. If my child's plan doesn't work, he/she will try another one to meet his/her goals.					
					Things I Do – Total Items 5 + 6 = _____

HOW I FEEL (Parent perception of how your child feels)

	Never	Almost Never	Sometimes	Almost Always	Always
1. My child feels good about what he/she likes, what he/she wants, and what he/she needs to do.					
2. My child believes that he/she can set goals to get what he/she wants.					
					Things I Do – Total Items 1 + 2 = _____
3. My child likes to make plans to meet his/her goals.					
4. My child likes to begin working on his/her plans right away.					
					Things I Do – Total Items 3 + 4 = _____
5. My child likes to check on how well he/she is doing in meeting his/her goals.					
6. My child is willing to try another way if it helps him/her to meet his/her goals.					
					Things I Do – Total Items 5 + 6 = _____

<u>WHAT HAPPENS AT SCHOOL</u> (Parent perception of what happens for child at school, if applicable)

	Never	Almost Never	Sometimes	Almost Always	Always
1. People at school listen to my child when he/she talks about what he/she wants, what he/she needs, or what he/she is good at.					
2. People at school let my child know that he/she can set his/her own goals to get what he/she wants or needs.					
Things I Do – Total Items 1 + 2 = _____					
3. At school, my child has learned how to make plans to meet his/her goals and to feel good about them.					
4. People at school encourage my child to start working on his/her plans right away.					
Things I Do – Total Items 3 + 4 = _____					
5. My child has someone at school who can tell him/her if he/she is meeting their goals.					
6. People at school understand when my child has to change his/her plan to meet his/her goal. They offer advice and encourage my child when he/she is doing this.					
Things I Do – Total Items 5 + 6 = _____					

<u>WHAT HAPPENS AT HOME</u> (Parent perception of what happens for child at home)

	Never	Almost Never	Sometimes	Almost Always	Always
1. People at home listen to my child when he/she talks about what he/she wants, what he/she needs, or what he/she is good at.					
2. People at home let my child know that he/she can set their own goals to get what he/she wants or needs.					
Things I Do – Total Items 1 + 2 = _____					
3. At home, my child has learned how to make plans to meet his/her goals and to feel good about them.					
4. People at home encourage my child to start working on his/her plans right away.					
Things I Do – Total Items 3 + 4 = _____					
5. My child has someone at home who can tell him/her if they are meeting their goals.					
6. People at home understand when my child has to change his/her plan to meet his/her goal. They offer advice and encourage him/her when he/she is doing this.					
Things I Do – Total Items 5 + 6 = _____					

APPENDIX E - STAGES OF READINESS ASSESSMENT

1. In the past month, have you been actively trying to take care of your health?
Yes / No

2. In the past month, have you been actively trying to learn how to take care of your health?
Yes / No

3. Are you seriously considering trying to take care of your health in the next 6 months?
Yes / No

4. Have you taken care of your health for more than 6 months?
Yes / No

Scoring

Stage	**Q1**	**Q2**	**Q3**	**Q4**
Precontemplation	No	No	No	
Contemplation	No	No	Yes	
Action	Yes on Q1 or Q2			No
Maintenance	Yes on Q1 or Q2			Yes

APPENDIX F - BACKGROUND INFORMATION QUESTIONNAIRE

Participant ID# P: _____ A: _____

Your Age_____

Number of children: _____ With autism spectrum disorder (ASD): _____

Relationship to adolescent with ASD: _____

Sex:
Male_____
Female_____
Other _____

Race:
(You may check more than one)
_____White
_____Black / African American / African
_____Asian
_____American Indian
_____Pacific Islander
_____Other

Ethnicity:
_____Hispanic / Latino / Latinx
_____Not Hispanic

Marital Status:
_____ married
_____ widowed
_____ separated
_____ remarried
_____ divorced
_____ single/never married

Child with ASD lives with:
_____ both mother and father
_____ mother only

_____ father only
_____ grandparent/grandparents
_____ other

Mother's Education:
_____ Did not complete high school
_____ High school graduate
_____ Some college/post-high school
_____ Complete college/bachelor's degree
_____ Post-baccalaureate

Father's Education:
_____ Did not complete high school
_____ High school
_____ Some college/post-high school
_____ Complete college/bachelor's degree
_____ Post-baccalaureate

Household annual income:
_____ $25,000 or less
_____ $25,001 to $50,000
_____ $50,001 to $75,000
_____ $75,000 to $100,000
_____ above $100,000

Access to family centered care (a partnership approach to health care decision-making between the family and health care provider):
_____ Yes
_____ No

Regarding your adolescent with ASD:

Your **child's** current age: _____
Your **child's** age when diagnosed with ASD: _____

Your **child's** current grade in school: _____

Your **child's** Sex:
Male_____
Female_____
Other _____

Your **child's** race:
(You may check more than one)
_____White
_____Black / African American / African
_____Asian
_____American Indian
_____Pacific Islander
_____Other

Your **child's** ethnicity:
_____Hispanic / Latino / Latinx
_____Not Hispanic

According to the DSM-5, ASD diagnosis includes challenges with social skills, repetitive behaviors, speech and nonverbal communication. Please answer the following questions with the above understanding of ASD.

Does your child have a chronic health condition in addition to their ASD diagnosis?
_____ Yes
_____ No

Child's <u>chronic health condition</u>(s) in addition to ASD:
Drop down options (check all that apply):
Physical (seizures, GI issues, diabetes, cardiovascular disorder, asthma, kidney disease, liver disease, blindness, deafness, arthritis)
Mental (anxiety, depression, ADHD, bipolar disorder, schizophrenia, OCD)
Developmental (intellectual disability, cerebral palsy, down syndrome, muscular dystrophy)
Other:_____
____

In past month, amount of time affected (outside of typical daily activity) by **<u>chronic health condition(s)</u>**:
_____ rarely or not at all
_____ sometimes
_____ usually/often
_____ always

Health insurance coverage:
_____ private

_____ public
_____ both private and public
_____ uninsured

Parent preferred contact method:
_____
Parent preferred survey packet completion online, hardcopy, and/or with PI:
_____

Youth preferred contact method:
_____
Youth preferred survey packet completion online, hardcopy, and/or with PI:
_____

APPENDIX G - AQ-10 (ADOLESCENT VERSION)

Please answer the following questions regarding your child.

Please tick one option per question only:		Definitely Agree	Slightly Agree	Slightly Disagree	Definitely Disagree
1	S/he notices patterns in things all the time				
2	S/he usually concentrates more on the whole picture, rather than the small details				
3	In a social group, s/he can easily keep track of several different people's conversations				
4	If there is an interruption, s/he can switch back to what s/he was doing very quickly				
5	S/he frequently finds that s/he doesn't know how to keep a conversation going				
6	S/he is good at social chit-chat				
7	When s/he was younger, s/he used to enjoy playing games involving pretending with other children				
8	S/he finds it difficult to imagine what it would be like to be someone else				
9	S/he finds social situations easy				
10	S/he finds it hard to make new friends				

SCORING: Definitely Agree (4), Slightly Agree (3), Slightly Disagree (2), Definitely Disagree (1) on each of the items 1, 5, 8, and 10. Definitely Disagree (4), Slightly Disagree (3), Slightly Agree (2), Definitely Agree (1) on each of the items 2, 3, 4, 6, 7, and 9. The higher the score, the more complex ASD (Allison, Auyeung, & Baron-Cohen, 2012).

APPENDIX H - CHILDREN WITH SPECIAL HEALTH CARE NEEDS (CSHCN) ASSESSMENT

All 3 Parts of at Least One Question (or, in the case of question 5, the 2 parts) Must Be Answered ‘‘Yes’’ In Order for a Child to meet CSHCN criteria for having a special health care need. “Yes” answers will be examined to determine complexity of child’s health care condition.

According to the DSM-5, ASD diagnosis includes challenges with **social skills, repetitive behaviors, speech and nonverbal communication.** Please answer the following questions with the above understanding of ASD. Please answer the items for your child’s health care condition(s), **not including treatment for ASD.**

1. Does your child currently need or use **medicine prescribed by a doctor** (other than vitamins)?
□ Yes → Go to Question 1a
□ No → Go to Question 2
1a. Is this because of ANY medical, behavioral, or other health condition?
□ Yes → Go to Question 1b
□ No → Go to Question 2
1b. Is this a condition that has lasted or is expected to last for at least 12 months?
□ Yes
□ No

2. Does your child need or use more **medical care, mental health, or educational services** than is usual for most children of the same age?
□ Yes → Go to Question 2a
□ No → Go to Question 3
2a. Is this because of ANY medical, behavioral, or other health condition?
□ Yes → Go to Question 2b
□ No → Go to Question 3
2b. Is this a condition that has lasted or is expected to last for at least 12 months?
□ Yes
□ No

3. Is your child **limited or prevented** in any way in his or her ability to do the things most children of the same age can do?
□ Yes → Go to Question 3a
□ No → Go to Question 4
3a. Is this because of ANY medical, behavioral, or other health condition?
□ Yes → Go to Question 3b
□ No → Go to Question 4
3b. Is this a condition that has lasted or is expected to last for at least 12 months?
□ Yes
□ No

4. Does your child need or receive **special therapy**, such as physical, occupational, or speech therapy?
□ Yes → Go to Question 4a
□ No → Go to Question 5

4a. Is this because of ANY medical, behavioral, or other health condition?
□ Yes → Go to Question 4b
□ No → Go to Question 5
4b. Is this a condition that has lasted or is expected to last for at least 12 months?
□ Yes
□ No

5. Does your child have any kind of emotional, developmental, or behavioral problem for which he or she needs or receives **treatment or counseling**?
□ Yes → Go to Question 5a
□ No
5a. Has this problem lasted or is it expected to last for at least 12 months?
□ Yes
□ No

APPENDIX I - EXECUTIVE FUNCTIONING SCALE

Participant ID: _____

How often does your child experience each of these problems? Please mark the number next to each item that best describes his/her behavior **DURING THE PAST 6 MONTHS**. If your child is currently taking medications for any psychiatric or psychological disorders, please rate his/her behavior based on how he/she acts while **OFF the medication.**

Items	**Never or Rarely**	**Sometimes**	**Often**	**Very Often**
1. Procrastinates or puts off doing things until the last minute	**1**	**2**	**3**	**4**
2. Has a poor sense of time	**1**	**2**	**3**	**4**
3. Wastes or doesn't manage his/her time well	**1**	**2**	**3**	**4**
4. Has trouble planning ahead or preparing for upcoming events	**1**	**2**	**3**	**4**
5. Has trouble explaining his/her ideas as well or as quickly as others	**1**	**2**	**3**	**4**
6. Has difficulty explaining things in their proper order or sequence	**1**	**2**	**3**	**4**
7. Can't seem to get to the point of his/her explanations	**1**	**2**	**3**	**4**
8. Doesn't seem to process information quickly or accurately	**1**	**2**	**3**	**4**
9. Makes impulsive comments	**1**	**2**	**3**	**4**
10. Likely to do things without considering the consequences for doing them	**1**	**2**	**3**	**4**
11. Acts without thinking things over	**1**	**2**	**3**	**4**
12. Doesn't stop and talk things over with him/herself before deciding to do something	**1**	**2**	**3**	**4**
13. Takes short cuts in his/her chores, schoolwork, or other assignments and does not do all that he/she is supposed to do	**1**	**2**	**3**	**4**
14. Does not put much effort into his/her chores, schoolwork, or other assignments	**1**	**2**	**3**	**4**
15. Seems lazy or unmotivated	**1**	**2**	**3**	**4**
16. Inconsistent in the quality or quantity of his/her work performance	**1**	**2**	**3**	**4**

17. Has trouble calming him/herself down once he/she is emotionally upset	**1**	**2**	**3**	**4**
18. Not able to be reasonable once he/she is emotional	**1**	**2**	**3**	**4**
19. Cannot seem to distract him/herself away from whatever is upsetting him/her emotionally to help calm down. Can't refocus his/her mind to a more positive framework	**1**	**2**	**3**	**4**
20. Not able to rechannel or redirect his/her emotions into more positive ways or outlets when he/she gets upset	**1**	**2**	**3**	**4**
				Total Score: _____

Higher scores indicate more significant executive function difficulties.

APPENDIX J - SOCIAL FACILITATION QUESTIONS

Adolescent:

What does your parent do to help you learn how to take care of your health? (select all that apply)
Drop down options: Teaches me about my medications; Teaches me about signs or symptoms to look for when I am getting sick; Teaches me how to complete a treatment; Teaches me to set-up doctors' appointments; Teaches me how to talk to my doctor; Shows me how to find out information about my health; Shows me how to set up reminders for medication or treatment; Teaches me how to eat right, exercise, or how to stay healthy; Teaches me how to manage my emotions; Nothing, my parents take care of all my health care needs for me; Other_____

What do you do on your own to take care of your health? (select all that apply)
Drop down options: Nothing, my parents take care of all my health needs; I talk to parent about wanting to take on more responsibility for my health; I get enough sleep, eat right, and exercise regularly; I monitor my health for signs or symptoms that I need to contact my doctor; I schedule my own appointments with my therapist when I feel I can't manage my emotions well; I use adaptive devices for my health, Other _____

Parent:

We understand that some parents of youth with ASD are starting to let their child take the lead in managing their own health care needs while others have not begun that process. The following questions relate to your child's preventative or chronic health care needs, as well as managing conditions that occur suddenly (ex: fever or an infection).

What do you do to help your child learn how to self-manage their health?
Drop down options: teach my child about how to take their medication; Teach my child how to monitor their health; Teach my child how to report symptoms to their doctor; Teach my child how to set-up appointments with their doctor or therapist; Teach my child how to find information about their health; Teach my child how to use adaptive devices for their health; Teach my child how to reduce stress or manage their emotions; I'm not now teaching my child these skills because I manage their health care; Other _____

Is there anything else you would like to tell us about teaching your child to learn how to self-manage their health?
_____

Some parents of children with ASD report feeling overwhelmed by managing their child's multiple health care conditions and necessary specialists.

What are your barriers to teaching your child how to self-manage their health? **Drop down options:** Never thought about teaching my child how to self-manage their own health before; Lack of time; Too many other competing teaching priorities for my child; My child has too many health concerns to self-manage; Lack of information about what to teach my child; No support from my child's doctor or nurse about how to do this; Too many other competing family priorities; Other _____

Is there anything else you would like to tell us about barriers to teach your child to learn how to self-manage their health?

_____

APPENDIX K - ELIGIBILITY AND COMPLETION CHECKLIST

Participant ID# P: _____ A: _____

Adolescent with ASD aged 12 to 22 years: Yes_____ No_____

Adolescent in sixth grade or above: Yes _____ No_____

Adolescent ability to read and write in English: Yes _____ No _____

Adolescent able to give assent: Yes _____ No _____

Youth able to give permission (if over 18 years old): Yes_____ No_____

Legal guardian (if applicable): _____

Youth Contact Information: _____

Adolescent survey preference: Online_____ In Person_____

Completed: Online _____ Hardcopy _____

Unable to complete study: _____

Reason: _____

Parent ability to read and write in English: Yes _____ No _____

Parent survey preference: Online _____ In Person_____

Parent able to give consent: Yes _____ No _____

Parent able to give permission for child to participate: Yes_____ No_____

Parent Contact Information: _____

Parent survey preference: Online _____ In Person_____

Completed: Online _____ Hardcopy _____

Unable to complete study: _____

Reason: _____

Family access to telephone and internet services: Yes _____ No _____

Contact Information: Parent: _____ Adolescent: _____

APPENDIX L - PARENT CONSENT TO PARTICIPATE IN RESEARCH

TEXAS
The University of Texas at Austin

UT Austin IRB Approved
Protocol Number: 2019-08-0087
Approved: 01/17/2020

Title of the Project: Health Self-Management for Adolescents with Autism Spectrum Disorder
Principal Investigator: Jamie L. Rock, MSN, RN, Doctoral Candidate, University of Texas at Austin, School of Nursing
Faculty Advisor: Heather Becker, PhD, Research Scientist, University of Texas at Austin, School of Nursing

Consent to Participate in Research

Invitation to be Part of a Research Study

You are invited to be part of a research study. This consent form will help you choose whether or not to participate. Feel free to ask if anything is not clear in this consent document.

What is the study about and why are we doing it?

The purpose of this exploratory study is to better understand how youth with autism spectrum disorder (ASD) learn to manage their health as they transition to adulthood. Up to 95% of individuals with ASD may have at least one co-occurring medical, mental, or developmental health condition(s). These health conditions can negatively impact the ASD individual if they are left untreated or undertreated. In addition, all youth need guidance in learning how to promote their health. This study seeks to understand what youth with ASD know about taking care of their health and how they are preparing to manage their future health, if at all.

What will happen if you take part in this study?

If you agree to take part in this study, you will be asked to:

- Complete online Background Questionnaire asking questions regarding demographic information and a short health history pertaining to your child's health.
- Complete online survey questions exploring your child's health and health behaviors from your perspective.
- Consent for your adolescent with ASD to complete a similar survey.

This study will take approximately 15-30 minutes to complete, which you and your child can access and complete at a time and place convenient to you.

Parents and youth participating in this study will have separate login accounts and be asked to complete the study independently. The researcher of the study may be reached (via email, phone, or phone/video conferencing such as Zoom or Skype) for additional support and help (online access issues, questions read aloud, clarification of questions) in cases where individuals need this added assistance. The PI is available for questions or support needed in completing the survey, but this support is limited to assure undue bias. Participants are given the option to complete the survey packet in the presence of the PI at a place of their choosing when added assistance is needed for your child, such as accessing survey packet, read questions aloud, and/or provide clarification of questions when needed. Participants also have the option to meet with PI to complete a hard copy of the study.

How long will this study take and how many people will be in the study?

Participation in this study will take approximately 15-30 minutes and include around 90 adolescent and parent pairs of participants.

What risks and discomforts might you experience from being in this study?

There are two minimal risks you might experience from being in this study.

They include informational risk associated with breach of confidentiality. Since survey data for this study are being collected through an online program, a computer breach is possible. However, the most recent security programs and firewall protection will be in place to eliminate such an event.

The survey questions in this study were designed to understand the adolescent's current health practices and participants may find some questions personal or difficult to answer. If you (the participant) become emotionally distressed while answering any of the survey questions, you may decide to take a break from the survey process and return to it another time. Participation in this study is voluntary. I (the researcher) have over ten years of experience working with people who have disabilities and other health problems. If you (the participant) become distressed while participating in this study, you may contact the researcher who can provide a referral list of community agencies available for needed support.

How could you benefit from this study?

You will receive no direct benefit from participating in this study. Society may benefit from the knowledge gained and participants will gain from contributing to the existing knowledge base.

What data will we collect from you?

As part of this study we will collect your name and contact information.

How will we protect your information?

We will protect your information by assuring no actual names will ever appear anywhere other than the informed consent/assent documents. The informed consent/assent documents will be stored in a locked file with only a coded link available to the investigator. Online survey data will be secured with the latest protective technology and files will only be accessible to participant (via passcode) and researcher. Your name and any other information that can directly identify you will be stored separately from the data collected as part of the project. Because this is a dissertation study, Committee Chair, Heather Becker, may also have access.

While the primary investigator of this study will do everything permitted by law to protect the participants privacy and confidentiality, there are a few unlikely incidents that would require us to break confidentiality:

Authorized persons from The University of Texas at Austin and the Institutional Review Board have the legal right to review your research records and will protect the confidentiality of those records to the extent permitted by law. If the research project is sponsored, then the sponsor(s) also have the legal right to review your research records.

Also, if you were to report that you currently experience physical or emotional abuse and need assistance, the researcher would have to disclose to authorities that you are a participant in this study in order to seek assistance for you. Lastly, we will in all cases take action necessary, including reporting to authorities, to prevent serious harm to yourself, your child, or others.

We will share your data with other researchers for future research studies that may be similar to this study or may be very different. The data shared with other researchers will not include information that can directly identify you.

We plan to publish the results of this study. To protect your privacy, we will not include any information that could directly identify you.

What will happen to the information we collect about you after the study is over?

We will keep your research data to use for future research. Your name and other information that can directly identify you will be kept secure and stored separately from the research data collected as part of the project.

How will we compensate you for being part of the study?

Each youth and parent participant will receive a $25 Target or Amazon gift card for their participation in this study. Compensation is awarded upon completion of the survey. You will be responsible for any taxes assessed on the compensation.

Your Participation in this Study is Voluntary

It is totally up to you to decide to be in this research study. Participating in this study is voluntary. Your decision to participate will not affect your relationship with The University of Texas at Austin. You will not lose any benefits or rights you already had if you decide not to participate. Even if you decide to be part of the study now, you may change your mind and stop at any time. You do not have to answer any questions you do not want to answer.

If you decide to withdraw before this study is completed, your electronic data will be deleted.

Contact Information for the Study Team and Questions about the Research

If you have any questions about this research, you may contact:

Jamie L. Rock
(801) 721-5640
AutismSM-project@austin.utexas.edu

Heather Becker, Dissertation Chair
hbecker@mail.nur.utexas.edu

Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

The University of Texas at Austin
Institutional Review Board
Phone: 512-232-1543
Email: irb@austin.utexas.edu

Please reference study number 2019-08-0087.

Your Consent

By agreeing to this document by clicking "yes" below, you are agreeing to be in this study. Make sure you understand what the study is about before you agree. We will give you a copy of this document for your records. We will keep a copy with the study records. If you have any

questions about the study after you agree to this document, you can contact the study team using the information provided above.

I understand what the study is about and my questions so far have been answered. I agree to take part in this study.

Yes ☐ No ☐

Future Research
May we contact you for future research opportunities? Please initial your selection:
____ Yes
____ No

Parental Permission for Child Participation in Research

Important Information about this Research Study

Things you should know:

- In order to participate, your child must be aged 12 to 22 years, diagnosed is autism spectrum disorder (ASD), in sixth grade or above, able to read and write in English.
- If you choose to allow your child to participate, your child will be asked to complete online survey questions exploring his/her heath and health behaviors from their perspective.
- Your child will be given an access code to answer the survey questions and allowed to answer the questions at a time and place of their choosing. No time limit is placed on completing the questions and they can leave and come back to the questions if extra time is needed. Additional support (accessing questions, reading questions aloud, clarification of questions) is provided by the PI (via face-to-face, email, phone, or phone/video conferencing such as Zoom or Skype), if needed. If completed at one time, the survey is estimated to take around 15-30 minutes to complete.
- Risks or discomforts from this research are no greater than those involved in everyday life.
- There are no direct benefits for participating in this study. However, indirect benefits include contributing to the knowledge about autism. Information gained from this study may be helpful for parents and children in caring for the youths' health.
- Taking part in this research study is voluntary. You or your child may decline to participate or stop participating at any time.

More detailed information may be listed later in this form.

Please take time to read this entire form and ask questions before deciding whether to allow your child to take part in this research study.

What will happen if your child takes part in this study?

If you agree to allow your child to take part in this study, your child will be asked to access an online account similar to what you have been asked to do. Your child will complete survey questions regarding their health. Youth participants will be asked fewer questions than their

parents. You and your child can contact the primary investigator for additional assistance, if needed.

How long will your child be in this study and how many children will be in the study?

Participation in this study will last as long as it takes him/her to answer the study questions, about 15 to 30 minutes. Around 90 youth will be enrolled in the study.

What risks and discomforts might your child experience from being in this study?

The risks your child might experience from being in this study are similar to those for parents. They are:
Informational risk associated with breach of confidentiality. Since survey data for this study are being collected through an online program, a computer breach is possible.

The survey questions in this study were designed to understand the youth's current health practices and participants may find some questions personal or difficult to answer. If your child (the participant) were to become emotionally distressed while answering any of the survey questions, he/she may take a break from the survey process and return to it another time. Participation in this study is voluntary. I (the researcher) have over ten years of experience working with people who have disabilities and other health problems. If your child (the participant) becomes distressed while participating in this study, you may contact the researcher who can provide a referral list of community agencies available for needed support.

The researchers will let you know about any significant new findings (such as additional risks or discomforts) that might make you change your mind about allowing your child to participate in this study.

How could your child benefit from this study?

Although your child will not directly benefit from being in this study, others might benefit because little is known about how youth with autism manage their health. This is also an opportunity for your adolescent to contribute to society's understanding of autism from your child's perspective.

How will we protect your child's information?

We will protect your child's information taking the same actions taken for your data. We will protect your child's information by assuring no actual names will ever appear anywhere other than the informed consent/assent documents. The informed consent/assent documents will be stored in a locked file with only a coded link available to the investigator. Online survey data will be secured with the latest protective technology and files will only be accessible to participant (via passcode) and researcher. Your child's name and any other information that can directly identify your child will be stored separately from the data collected as part of the project. Because this is a dissertation study, Committee Chair, Heather Becker, may also have accessibility.

While the primary investigator of this study will do everything permitted by law to protect the participants privacy and confidentiality, there are a few unlikely incidents that would cause confidentiality to be broken:

Authorized persons from The University of Texas at Austin and the Institutional Review Board have the legal right to review your child's research records and will protect the confidentiality of

those records to the extent permitted by law. If the research project is sponsored, then the sponsor(s) also have the legal right to review your research records.

Also, it is possible that if your child were to report that he/she currently is experiencing physical or emotional abuse and needs assistance, the researcher would have to disclose to authorities that your child is a participant in the researcher's study in order to seek assistance for him/her. Lastly, you should understand that we will in all cases take action necessary, including reporting to authorities, to prevent serious harm to yourself, your child, or others.

We will share your child's data with other researchers for future research studies that may be similar to this study or may be very different. The data shared with other researchers will not include information that can directly identify your child.

We plan to publish the results of this study. To protect your privacy, we will not include any information that could directly identify your child.

What will happen to the information we collect about your child after the study is over?

We will keep your child's research data to use for future research. Your child's name and other information that can directly identify them will be kept secure and stored separately from the research data collected as part of the project.

How will we compensate your child for being part of the study?

Your child will receive a $25 Target or Amazon gift card. Parents will also receive a $25 Target or Amazon gift card for their participation in the study. Compensation will occur upon completion of survey questions. You will be responsible for any taxes assessed on the compensation.

Your Child's Participation in this Study is Voluntary

It is totally up to you and your child to decide to be in this research study. Participating in this study is voluntary. The decision to participate will not affect your or your child's relationship with The University of Texas at Austin. You and your child will not lose any benefits or rights you already had if you decide not to participate. Even if you decide to allow your child to be part of this study now, you may change your mind and stop at any time. Your child does not have to answer any questions they do not want to answer.

If you decide to withdraw your child from the study before it is completed, please contact the primary investigator promptly and data will be deleted.

Contact Information for the Study Team and Questions about the Research

If you have any questions about this research, you may contact:

Jamie L. Rock
(801) 721-5640
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Contact Information for Questions about Your Rights as a Research Participant

If you have questions about your rights or your child's rights as a research participant, or wish to obtain information, ask questions, or discuss any concerns about this study with someone other than the researcher(s), please contact the following:

The University of Texas at Austin Institutional Review Board

Phone: 512-232-1543
Email: irb@austin.utexas.edu

Please reference study number 2019-08-0087.

Your Permission

By agreeing to this document, you are agreeing to allow your child to be in this study. Make sure you understand what the study is about before you agree. We will give you a copy of this document for your records. We will keep a copy with the study records. If you have any questions about the study after you agree to this document, you can contact the study team using the information provided above.

I understand what the study is about and my questions so far have been answered. I agree to allow my child take part in this study.

Yes ☐ No ☐

APPENDIX M – ADOLESCENT CONSENT/ASSENT TO PARTICIPATE IN RESEARCH

TEXAS
The University of Texas at Austin

UT Austin IRB Approved
Protocol Number: 2019-08-0087
Approved: 01/17/2020

Title of the Project: Health Self-Management for Adolescents with Autism Spectrum Disorder
Principal Investigator: Jamie L. Rock, MSN, RN, Doctoral Candidate, University of Texas at Austin, School of Nursing
Faculty Advisor: Heather Becker, PhD, Research Scientist, University of Texas at Austin, School of Nursing

Consent to Participate in Research

Why are we meeting with you?

A research study is usually done to find a better way to treat people or to understand how things work. You are being asked to take part in this research study because you are an adolescent with autism between the ages of 12 to 22 years, are in 6th grade or higher, and can read and write in English.

This form may have some words that you do not know. Please ask me to explain any words you do not know.

What is the study about?

We are doing this study to learn what people on the autism spectrum think about taking care of their health and health conditions. We are asking you to help because we don't know very much about how youth your age expect to take care of their health.

What am I going to be asked to do?

If you agree to be in this study, you will be asked to go on the computer and answer questions about what you do to take care of your health. We want to know how you feel about taking care of your health and what you do with and without your parents and others to learn how to care for your health.
This study will take about 15-30 minutes to complete and there will be about 90 adolescents and their parent in this study. Adolescents and parents will have a separate online account. The questions we will ask are only about what you think and feel. There are no right or wrong answers because this is not a test. Your parent(s) cannot see your answers and will not be told how you answered.
If you struggle with accessing the survey online, don't quite understand what the question is asking, or need the question read to you out loud, you have the option to contact (via email, phone, or phone/video conferencing such as Zoom or Skype) or meet with the PI to receive assistance and complete the survey. Participants also have the option to meet with PI to complete a hard copy of the study.

Will any parts of this study make me feel bad?

Sometimes talking about these things makes people upset. You can skip any questions you do not want to answer. If you do become upset, let us know and we can help you.

How will this study help me?

This study won't help you, but your answers to these survey questions will help others better understand health and autism. Most people with autism have another health condition that can cause problems for them if the health condition is not cared for properly. Understanding how

you and other people like you learn how to take care of your health can help society gain knowledge about autism.

What happens to my information collected for the research?

We will limit the use of your personal information to people who have a need to review this information. We cannot promise to keep everything a secret, but we will work to keep your name and other information private. Your responses may be used for a future study by us or we may share your responses with other researchers, but we won't give them your name.

Will you tell anyone what I say?

If you tell us that someone is hurting you, the law says that we have to let other people know so they can help you. If you tell us you might hurt yourself or someone else, then we will have to let people know.

Will I get anything to participate?

You will get a $25 gift card for your participation in completing the survey questions. You will receive the gift card when the survey is completed.

Do I have to be in this study?

You do not have to be in this study. It is up to you. You can say okay now and change your mind later. No one will be upset if you do not want to do this. All you have to do is tell us you want to stop.

Who do I talk to if I have questions?

You can ask any questions at any time. You can ask now or later. Just tell the researcher when you contact them, or ask your parent or another adult to contact:

Jamie L. Rock
(801) 721-5640
AutismSM-project@austin.utexas.edu

Heather Becker, Dissertation Chair
hbecker@mail.nur.utexas.edu

Youth Consent

Before you say yes or no to being in this study, we will answer any questions you have now.

If you do not want to be in this study, just say so, and do not agree this form by clicking "no" below.

If you click "yes" below, it means you agree to participate in this study and you will be directed to the survey questions.

Yes ☐ No ☐

If you are 18 years or older and have a legal guardian, they need to sign below for you to be in the study.

Legally Authorized Representative Permission

By signing this document, you are agreeing to the person's named above participation in this study. Make sure you understand what the study is about before you sign. We will give you a copy of this document for your records. We will keep a copy with the study records. If you have any questions about the study after you sign this document, you can contact the study team using the information provided above.

I understand what the study is about and my questions so far have been answered. I agree for [the person named below] to take part in this study.

_____
Printed Subject Name

_____
Printed Legally Authorized Representative Name and Relationship to Subject

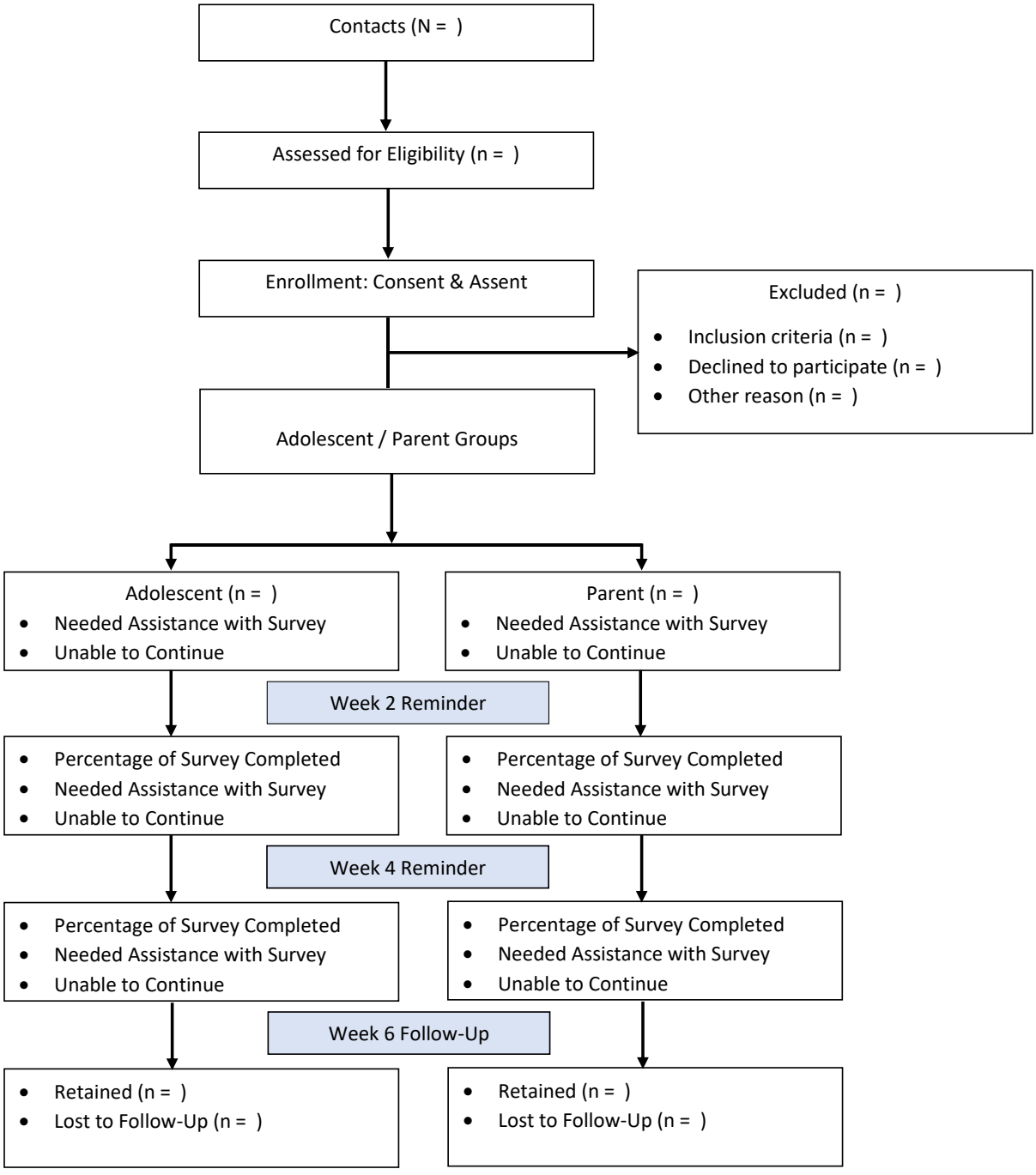
_____
Signature Date

APPENDIX N - RECRUITMENT LOG

Participant ID#: _____

Participant Activity	Adolescent	Parent
Met eligibility criteria		
Declined to participate		
Complete assent/consent		
Received identification #		
Received login information		
Complete survey by week 2		
2-week reminder		
Complete survey by week 4		
4-week reminder		
Complete survey by week 6		
6-week reminder		
Complete survey online		
Complete survey in-person		
Complete survey hardcopy		
Read questions aloud		
Answered question(s)		
Question clarification		
Accessing survey		
Other		
Unable to complete survey		
Survey complete		
Disperse funds		

APPENDIX O – STUDY RETENTION LOG



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